

**CREATIVE COPING: A DESCRIPTION OF EXPERIENCES OF FAMILIES COPING
WITH CHRONIC ILLNESS IN A CHILD**

A Dissertation

by

MARNIQUE MCGOUGH

Submitted to the Office of Graduate Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

May 2005

Major Subject: Educational Psychology

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ABSTRACT

A Description of Experiences of Families Coping with Chronic Illness in a Child.

(May 2005)

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Chronic illness impacts numerous families in the United States. Children are increasingly among those affected by a chronic illness. The families undergo trials and experiences that tax their coping skills and require extensive coping strategies.

This research project explored how families cope with chronic illness in one of the children in the family. The objective of the research project was to use the method of case study to examine the everyday lives, perceptions, and coping strategies of the family members as they deal with the realities of the effects of a child's illness on a daily basis. Three families were studied using the case study format. Through interviews, observations, and investigation of data, the researcher gathered pertinent information about the participants' lives and experiences.

Emergent themes were identified from the facts gathered. These themes included information and suggestions that various participants offered. Included among the emergent themes were the following titles: alarming environment, redefined realities, relational requests, valuable individual, coping concoctions,

as well as awareness and advocacy. The study's emergent themes were divided into numerous subcategories. The multiple realities that the family members face is evidenced in the number of issues and themes that emerged from the study.

This research project gives additional insight into the reality of the lives of families experiencing chronic illness in one of the children. Suggestions and observations by the participants could be useful for family, friends, medical professionals, educational systems, and support groups that interact with families facing similar trials. The descriptive style of the study lends itself to the vicarious interaction of the reader to the circumstances of the participants. This format allows the reader to transfer knowledge to his or her own experiences. The study could further be useful by offering detail to the existing knowledge base, in addition to aiding in the development of theory.

*To My Parents
Trish & Scott McGough
For Creating Me
&
Nurturing Creativity
In Me*

*To My Boys
Chase & Colten
My Most Precious
& Incomparable
Creations*

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I would not have initiated or completed this endeavor without the love and everlasting support of my parents. They encourage me both emotionally and intellectually to continue. They have instilled in me the confidence to conquer what seem at times daunting challenges. The hands-on help and “keep goings” have allowed this study to come to completion. Thanks mom and dad for the company on the countless late nights writing, trips to campus and babysitting the boys. My mom believes in “hand-holding” through life; this project is a manifestation of that hand-in-hand philosophy.

My boys are the bright light in my life. Chase, with his humor and quick wit, has made me laugh when only crying seemed possible. Colten, with his giving heart and transparent love, is an example to all who meet him of genuine joy. I am truly alive with these children in my life. My schooling was completed and dissertation written while wagging them around campus, using their precious stories as material while teaching child development, and watching them entertain themselves with swords as I complete the final chapters. It is my hope that they will use their God-given talents to help others through this life.

My brother, J., and his family, Pam, Reid and Kayla, have opened their home and given the boys and me a place to rest when we needed to be close to my studies. Thank you for your loving support and open doors through the years.

My aunt and uncle, Kaye and Bob, have helped me with practical heart matters and offered inspiration through their active lives. When there is a lull in productivity, it helps to have others to look to as an example.

There are friends and family that have listened, hour after hour, about my studies and my efforts to complete them. Thank you for your patience, and for loving me enough to bear with me through its completion. Thanks Mike for overcoming the computer crises, and Chuck for running my endless errands!

The families, who have welcomed me into their innermost thoughts, insecurities, fears, and tears, have taught me a great deal about love and endurance. Their willingness to be transparent and participate in this study, in hopes of helping others, demonstrates their strength of character and selflessness. This project was not possible without each of you.

My boss, Richard Weir, has given me an opportunity to work as a child life specialist with hospitalized children. He has allowed my talents to find a home at work. I learn invaluable lessons through the families I encounter at the hospital. Thank you for your flexibility as I completed this task alongside my regular job.

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My life-long mentor and inspiring teacher, Dr. Nash, has opened my eyes to the possibilities of creativity and opportunity that this world holds. Through example after example, I have seen others achieve their goals at the instigation and inspiration of this man. I have been fortunate to be one of his “mentees”. His genuine care and love is apparent through his practical actions. Thank you for keeping me in gear at times when my life seemed to spin out of control.

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Thanks to God for giving me all I need to complete this mission.

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CHAPTER I

INTRODUCTION

The purpose of this study was to explore how families cope with chronic illness in one of the children in the family. The objective of this research project was to use the method of case study to examine the everyday lives, perceptions, and coping strategies of the family members as they deal with the realities of the effects of a child's illness on a daily basis. Specific objectives were as follows:

- A. To explore the realities of the family's lives in coping with a chronic illness in one of the children.
- B. To investigate the perceptions of the family members of their situation, coping skills, and needs.
- C. To explore the strategies that a family employs in order to further the family and the individuals within the family in the adjustment process.
- D. To investigate, from the family's perspective, areas of perceived strengths and weaknesses of the health professionals when assisting the family in coping with the illness and life changes.
- E. To explore the possibilities of how individuals and groups outside the family can assist in the adjustment process.

STATEMENT OF THE PROBLEM

The term coping brings with it different connotations for various people. Often times it brings to mind the idea of "getting by" or "dealing with" a situation in life. The concept of coping is often addressed in the literature without offering a

This dissertation follows the style of *The Journal of Clinical Child and Adolescent Psychology*.

definition. Recent definitions focus on the notion of competence and coping in specific situations (Hops, 1983).

In Ziemer's (1982) article on coping, it is concluded that "professionals are converging on a definition of coping" (p. 4). The central definition states that: "coping refers to efforts to master conditions of harm, threat or challenge when a routine or automatic response is not readily available" (Monat & Lazarus, 1977, p. 8).

One of the most cited models dealing with the issue of coping is the process model of stress and coping developed by a group of psychologists including R.S. Lazarus. The process model of stress and coping views the individual as actively and creatively seeking to manage stressors as they are encountered. Although this general model (Lazarus & Folkman, 1984) is concerned with the coping processes of an individual, it has been used since the mid 1980's to research families with disabled children.

In focusing on issues of coping, hospitalization, and chronic illness, there is a distinct population of children who must face these experiences on a regular basis. Due to the technological and medical advancements of the last several decades, the survival rate of children with illnesses has increased. In the United States, many children with chronic illnesses are surviving into adulthood (Meleski, 2002). This fact leads to the reality that many of these children are now faced with coping with a chronic illness or disability (Hostler, 1991; Rose & Thomas, 1987; Stein, 1989). According to the U.S. National Center for Health Statistics (1994), in 1992, approximately 292 million people in the United States

were affected by chronic illnesses. Harper (1991) reports that between 10% and 12% of the United States population includes children with chronic illness and/or physical disabilities. In fact, estimates indicate that 31% of children in the United States are faced with one or more chronic illnesses (Melnyk, Moldenhouer, Feinstein, & Small, 2001). These statistics indicate that 20 million children under the age of 18 suffer from some type of disability or chronic condition (Statistics, 2001). Out of those children, 1 million require long-term comprehensive care, while 3% of children under the age of five and 7% of children ages five to 17 are limited in their activities due to chronic health conditions according to the U.S. Federal Interagency Forum on Child and Family Statistics (www.childstats.gov), America's Children 2001.

Chronic illnesses are considered the foremost health problems in our country today (Pollock, 1993). A number of researchers have noted a significant increase in families coping with the chronic illness of one of its members (Gilliss, Rose, Hallburg, & Martison, 1989). Almost without exception, these chronically ill members are cared for by their families. Over the past 50 years, there has been a shift from care in hospitals or institutions, to homes and communities (Meleski, 2002). These facts illustrate the need for increasing attention to the families of children dealing with chronic illnesses.

Most relevant studies involving the care of chronically ill children utilize several different approaches. One is the disease-specific approach, which focuses on the parents of children with a specific illness, such as cancer or asthma. Another is the generic approach, which encompasses a number of

different illnesses. This approach is based on the notion that the challenges of parenting chronically ill children have commonalities. The latter alternative has the “potential to help families by focusing on coping strategies, providing health care team members with common adaptive goals for parents, and supplying a basis for future development” (Meleski, 2002, p. 49).

Much research has been conducted over the last thirty years focusing on the stressors that face caring for a chronically ill or disabled child (Beresford, 1994). These studies have highlighted the problems that are inevitably involved in the process of caring for the ill child, addressing such questions as “What problems do these families show?” (Miller et al., 2000, p. 3). Some recent researchers have seen the need for a shift in the emphasis from the description of the stressors and their negative effects. Instead, an emphasis should be placed on exploring how families cope with the surmounting problems (Beresford, 1994; Miller et al., 2000).

An abundance of the practical literature focuses on the health care professionals’ role in assisting the patients while they are in the health care facility (Snowdon & Kane, 1995). This role is greatly needed and beneficial. In addition, many studies have been conducted which indicate the benefit of family involvement when children are dealing with hospitalizations (Caty, Ellerton, & Ritchie, 1984; Hostler, 1991; Miles & Carter, 1985). It is imminent to recognize that, in the actual lives of the families in dealing with chronic illness, life beyond the hospital exists and is extremely demanding. Providing optimal care translates into how successfully the health care professionals can assist the family and the

child cope with the new challenges they face when they leave the hospital (Worthington, 1995). Fewer studies have focused on the day-to-day realities of coping with a chronic illness on a regular basis (Snowdon & Kane, 1995).

PURPOSE OF THE STUDY

This study was designed to examine and describe the experiences of families who face a chronic illness in one of the children. The findings of this research study will give insight into the complex circumstances involved in the lives of families coping with a child with a chronic illness. Themes will be identified from the information and data collected from the observations of the families. The results of this study will provide parents, children, medical staff, and educators with additional information about how families cope with chronic illness in a child. These implications will assist individuals in discovering possible interventions that may enhance the experiences of families undergoing such trials on a daily basis.

RESEARCH QUESTIONS

1. What are the perceived needs of the parents and children in families coping with a child with a chronic illness?
2. How are the everyday lives of the various members of the family affected by the illness?
3. What strategies do the family members use in dealing with the life changes?
4. What effects did the illness have on the individuals and family functioning?
5. What are the perceived obstacles or difficulties that the family members attribute to the chronic illness?
6. How do the individuals and family function during this stressful time?
7. What strengths and weaknesses of the health care professional are perceived by the family in regards to aiding them in the adjustment process?
8. What recommendations or suggestions do the family members have for the organizations or individuals including health care professionals, educators, family members, formal support groups, friends which could serve to help families coping with an ill child?

DEFINITION OF TERMS

COPING: Lazarus and Folkman (1984) defined coping as: "...the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person" (p. 283).

CHRONIC ILLNESS: A chronic condition is generally one that lasted or is expected to last more than a defined period of time, usually three months or longer (American Academy of Pediatrics, 1993).

TRUSTWORTHINESS: Trustworthiness is the degree to which a study is considered reliable and valid.

MEMBER CHECKING: The process of allowing participants to test the categories, interpretations and conclusions in an effort to establish the accuracy and credibility of the research.

TRIANGULATION: The process of collecting information about the same events from different perspectives in order to ensure credibility in the study.

REFERENTIAL ADEQUACY MATERIALS: The collection of materials including such things as documents or photographs to create a holistic view of the context of the research.

PROLONGED ENGAGEMENT: An extended period of time spent in a research setting in order for the researcher to understand the daily events of the subjects from the subject's unique perspective.

PERSISTENT OBSERVATION: The researcher's constant pursuance of different and emergent data through consistent analysis. This provides depth to the study.

PEER DEBRIEFING: A process in which the researcher talks to an objective party who has a general understanding of the study. The role of the peer debriefer is to discuss emerging themes and hypothesis, as well as listen to the researcher's concerns and ideas.

TRANSFERABILITY: The extent to which the reader can transfer the information in the study to his or her own experience or situation.

THICK DESCRIPTION: The use of descriptive writing including the specific sights and sounds surrounding an event in an effort to increase the reader's sense of applicability to his or her own life, thus enhancing the study's transferability.

LIMITATIONS

Through the use of thick description, this study seeks to provide a detailed depiction of the experiences of the participants. This detailed description will offer the reader the opportunity to transfer the findings to his or her own experiences when applicable. However, due to the nature of the distinct and unique social situations, one limitation of this study is that it is inappropriate to form generalizations from this type of research. The goal of this study is to offer a rich description of the experiences and perceptions of families dealing with the chronic illness of a child. Therefore, the results of this study have the potential to aid in the development of theory and to reveal new insights and further detail to the research on families' experiences with a child's chronic illness.

DESIGN OF THE DISSERTATION

This dissertation is divided into five main chapters. Chapter I includes the introduction to the study of families coping with a chronic illness in one of the children. This chapter gives a brief history of the need for such a study, the purpose of the study, research questions guiding the study, definitions of relevant terms, and the limitations of a case study conducted in this qualitative manner. Chapter II follows the introduction with a review of the literature that relates to the research project. Chapter III discusses the methodology and procedures adhered to in conducting the study. It contains the research design of the case study, the instruments, and the procedures, including interviews and observations. Also included in the chapter is an explanation of the analysis of the data.

Chapter IV is a descriptive chapter relating the interviews and observations conducted throughout the research process. The researcher writes in first person in this chapter in an effort to create an atmosphere that enhances the reader's vicarious experience with the topic at hand. This effort seeks to increase the readability and transferability of the information depicted in the chapter.

Three families participated in this research project. Individual interviews from the members of the families will give the reader insight into the different perspectives offered from the respective family members including ill children, parents, and siblings of those chronically ill children. Pseudo names were assigned to the participants in order to protect their confidentiality. Observations and interactions are also detailed in this chapter. Chapter V, the final chapter,

consists of a summary, research questions, emergent themes, recommendations for further studies in this area of research, and a conclusion.

CHAPTER II

REVIEW OF THE LITERATURE

The concept of coping is often mentioned in the literature without offering a definition. Recent definitions focus on the notion of competence and coping in specific situations (Hops, 1983). Caty, Ellerton and Ritchie (1984) consider coping as an attempt to adapt in complicated situations.

Miles and Carter (1985) define coping as the “process individuals use to adapt to a stressful life situation” (p. 14). Coping may also be defined as the cognitive, behavioral, and emotional responses to a crisis which serve to master, reduce, or tolerate the demands created by the situation (Lazarus, 1966; Lazarus & Launier, 1978; Moos & Tsu, 1977).

Mengel (1982) notes that the idea of coping has broadened to include the overall person rather than simply the physical response to stress. Coping is viewed as a dynamic process including biological, psychological, and social variables. Coping is seen as a set of behaviors, both conscious and unconscious that a person adopts when facing stress. These behaviors are part of the person’s efforts at improving the situation and managing the stress-resultant emotions (Lazarus, 1981).

Ziemer (1982) concludes “professionals are converging on a definition of coping” (p. 4). The definition states: “coping refers to efforts to master conditions of harm, threat or challenge when a routine or automatic response is not readily available” (Monat & Lazarus, 1977, p. 8). Melnyk et al. (2001) claims that multiple experts in the field are in agreement that coping has two parallel functions

including: emotional coping, the regulation of emotional responses and functional coping, which involves solving problems.

PROCESS MODEL OF STRESS AND COPING

One of the most cited models dealing with the issue of coping is the process model of stress and coping developed by a group of psychologists. This group was led by Richard Lazarus in the early 1960's. By the mid 1980's, a great deal of research validated the model created by Lazarus. In the 1990's, the model was acknowledged as the most comprehensive model of stress, adjustment and coping (Coyne & Smith, 1991; Slavin, Rainer, McCreary, & Gowda, 1991). The central feature of this model is that the "process of coping mediates the effects of stress on an individual's well-being" (Beresford, 1994, p. 174).

Lazarus and Folkman (1984) defined coping as: "...the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person" (p. 283). According to the process model of stress and coping, the individual creatively attempts to handle stressors as they are encountered. In addition to studying individuals, the model has been useful in studying the families of disabled children since the mid 1980's (Lazarus & Folkman, 1984). The following diagram is adapted from Beresford's (1994) article on coping (p. 173). The diagram depicts the coping process.

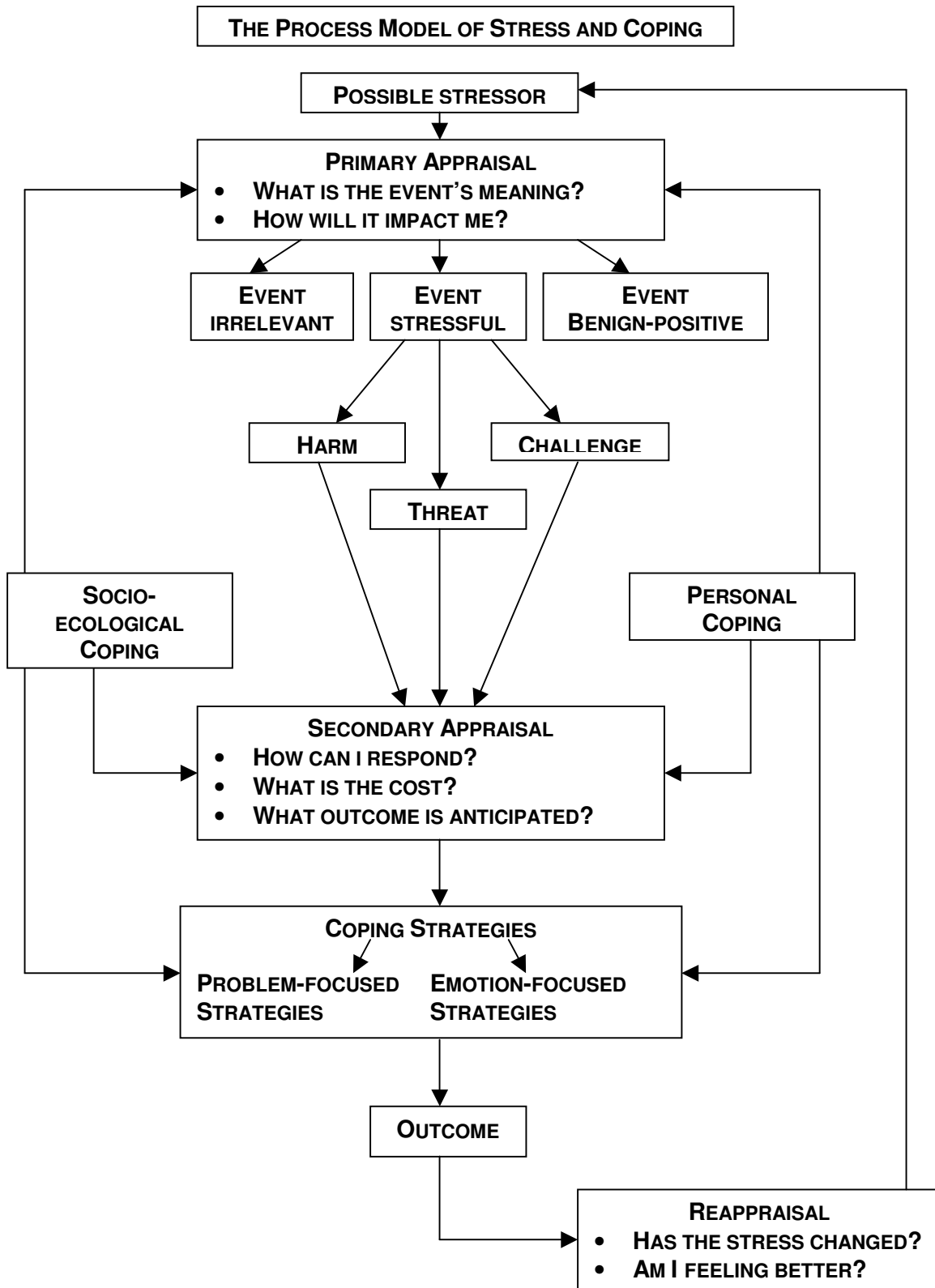


Figure 1. The Process Model of Stress and Coping (adapted from Beresford, 1994, p. 174).

This model includes four concepts that are emphasized in the definition. The first concept is that coping is a process, or interaction between the person and the environment. The notion of this concept is that coping is not static, but rather changes with the situational demands and the various cognitive appraisal of the individual.

The second feature of the stress and coping model is that coping is viewed as management of the problem rather than mastery of the problem. This realistic appraisal takes into account that issues exist that cannot be mastered, yet can be managed. This is especially true for parents caring for children with chronic illnesses. Many of the circumstances of the child's physical conditions are not situations that can be resolved. However, there are positive techniques to learn which can assist the family in dealing with the condition so that it is not a major problem in the daily functioning of the family.

The third aspect of the model of coping presented by Lazarus and Folkman (1984) is the sense of appraisal. Appraisal is the notion that an event is only stressful if it is perceived as such. The way a person views an event is influenced both by situational and personal factors. The amount of financial resources that one family has compared to that of another family would be an example of a situational factor. This situational factor will likely impact the family's appraisal of what will be a financial burden. A personal factor may also influence the coping abilities of one person in comparison to another. For example, one parent's previous experiences and exposures to similar situations can greatly determine how that person will view the illness of their child.

The last aspect of the Lazarus & Folkman's model of stress and coping is that coping is a mobilization of effort. This concept includes both "cognitive and behavioural efforts to manage (reduce, minimize, master, or tolerate) the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the person's resources" (Folkman, Lazarus, Gruen & DeLongis, 1986a, p. 572).

PERSONAL COPING RESOURCES

Personal coping resources are an important aspect of the coping process. These resources include both physical and psychological factors. Examples of these personal resources would include "...physical health, morale, ideological beliefs, previous coping experiences, parenting skills, intelligence, and personality characteristics" (Beresford, 1994, p. 176).

Physical Health

The physical health of the parents of the sick child is especially important since the care taking of a chronically ill child is constantly physically demanding. (Brown & Hepple, 1989). If the parent becomes ill, the care taking of the sick child is often hindered. The parent's lack of sleep is possibly the most significant physical problem. Caring for a chronically ill child offers little opportunity for the parents to have a break from the stress, and revitalize their own physical well-being.

Approaches to Life

Several different approaches to life have been considered important resources (Beresford, 1994). A positive association is found between adjustment

and the parent's ability to focus on the positive aspects of their child and their situation. Another important resource is the ability of the parents to adopt a daily approach to life rather than focusing on a plan for the future (Bregman, 1980; Brown & Hepple, 1989).

Religious Beliefs

In addition to the mentioned life outlooks, religious beliefs are considered an important resource, not only at the time of diagnosis, but also in the continuous care of a chronically ill child (Beresford, 1994). Research shows that religious beliefs play an important role in how families handle stress (McCubbin, 1979).

Personality and Humor

Personality is a very complex concept, and has only been investigated to a certain extent in relation to how it relates to coping resources. Optimists, those people that expect that the best will happen, are more likely to practice more adaptive coping strategies including social support and problem-focused coping (Scheier & Carver, 1985). Pessimists were more inclined to use strategies such as denial and expression of feelings. An additional trait that seems beneficial in dealing with stress is a sense of humor. Humor is often stated as a coping resource for parents of a disabled child (Farran, Metzger, & Sparling, 1986; Libow, 1989).

Locus of Control

Beliefs about locus of control affect many areas of an individual's life. People who believe that they influence the path of their lives are viewed as

having an internal locus of control. Those people with an external locus of control view their lives as determined by outside factors, of which they cannot change. The research suggests that internal locus of control beliefs seem more adaptive than external beliefs (Lefcourt, 1989; Wheaton, 1980).

SOCIO-ECOLOGICAL COPING RESOURCES

The second set of coping resources is considered socio-ecological coping resources (Beresford, 1994). These coping resources are an element of the individual's environment or social situation. Examples of such resources would include: the marital relationship, social support, practical resources and economic conditions (Beresford, 1994).

Social Support of Families

Researchers have explored the social support of families raising a disabled child. Parents of disabled children consider themselves to be isolated and lonely (Bradshaw & Lawson, 1978; Melnyk et al., 2001). Social isolation is often one of the most taxing facets of caring for a disabled child (Pahl & Quine, 1985). These parents may be afraid to leave their child. Family members and friends may not be sure of how they can help. Practical support from the extended family, especially in the form of caring for the children, is important (Brown & Hepple, 1989). Another factor contributing to parental isolation is exhaustion, which causes the parent to lack the time or energy resources necessary for pursuing friendships.

COPING STRATEGIES

Coping strategies are an essential aspect of a family dealing with long-term illness in their child's life. Coping strategies include actions, behaviors and thoughts used to deal with a stressor (Folkman et al., 1986a). There are two types of coping strategies: emotion focused coping and problem-focused coping (Beresford, 1994). Emotion-focused coping is an attempt to ease upsetting or painful emotions resulting from stressors. Emotion-focused strategies seek to alleviate feelings on the somatic level or the level of feelings. Examples of emotion-focused coping would be reading a funny book or watching a humorous movie on the feelings level. An example on the somatic level would be to reduce physical stress by smoking a cigarette or taking a bubble bath to relax.

Problem focused coping functions to adjust the "troubled person-environment relation causing the distress" (Folkman et al., 1986b, p. 993). These functions can be either internally or externally directed. Cognitive restructuring, or redefining the stressor, is an example of an internal function. Asking for help would be considered an externally directed coping function. A coping strategy can serve both functions at different times, depending on the situation. There are also situations where a coping strategy will serve both functions simultaneously.

Parental Coping Strategies

Bregman (1980) conducted a study that gives insight into parental coping strategies. She lived for four days with six different families whose child or children had a neuromuscular disease. The families adopted a day-by-day mentality rather than attempting to focus on long-term issues. They waited for a

need to arise from the child, dealing with the need at the time. The parents attempted to maintain as normal of a lifestyle as possible. In order to accomplish this feat, strategies including educating the neighbors and maintaining the child's social interactions were exercised. A third issue the parents addressed was to minimize the family's vulnerability by seeking information and superior options for their child's care and education. Another important aspect of parental coping was to develop coping resources. The parents considered both informal and formal support networks helpful. Financial, emotional and practical support were each beneficial.

Another study by Brown and Hepple (1989) reported parents' views about the coping strategies that best helped them handle a child with a learning disability or multiple disabilities. Talking to one's spouse was the most frequently mentioned strategy. This strategy relieved stress as well as assisted with decisions regarding care of the child. Cognitively, the parents would remind themselves "It could be worse". Restructuring the circumstances using humor was another strategy mentioned. Focusing on the positive aspects of the child also helped the parents cope with the difficulties. Once again noted was the one day at a time philosophy, not focusing on the future. The extended family was also appreciated as important in the practical and emotional aspects of dealing with the complex circumstances. Formal support was used as a coping strategy, but often as a last resort or in a crisis situation.

III Child's Coping Strategies

Boyd and Hunsberger (1998) completed a qualitative research study with six children ranging from 10 to 13 years old. Each of these chronically ill children faced the realities and stresses of repeated hospitalizations. The participants were interviewed, as well as completed a drawing and kept a journal. The children acquired both cognitive and behavioral coping strategies with which to deal with their illnesses. In addition, the children were able to identify and describe how family, friends and hospital staff enhanced their coping.

Some of the children's perceived stressors were determined in this study by asking them questions relating to the "worst part(s) about being in the hospital, and/or the things that happened in the hospital that worried or upset them" (Boyd & Hunsberger, 1998, p. 334). The following is a list of the perceived stressors identified by the children: IV's, invasive procedures and needles, surgery, fear of death, lack of independence, hospital environment (noise, lack of privacy), loss of control, isolation from peers, and lack of activities and boredom.

Behavioral Coping Strategies

Once the perceived stressors were identified, the coping strategies the children used in dealing with the issues were determined. The children recognized both behavioral and cognitive strategies they used in handling their situations. Behavioral distraction was mentioned by all of the participants. The children cited times when they practiced this technique in dealing with situations such as invasive procedures or pain. They also used distraction to assist them in overcoming the boredom that the hospitalization produced. Some of the

examples of distraction techniques included “deep breathing, watching TV and videos, listening to music, going for a walk, playing games, doing crafts, and ‘bugging the nurses’” (Boyd & Hunsberger, 1998, p. 335).

Another coping strategy mentioned by all of the participants was seeking social support. Primarily, the children focused on seeking social support from their friends. This could be due to the fact that the parents of most of the children were already with them, alleviating the need for the child to seek the parental support. Avoidance/resistance was an additional strategy the children employed. Examples of these coping techniques were taking naps, or being resistant to a painful procedure. Submission and cooperation were seen by the children as necessary at times. There were times when the kids realized they would have to let the doctors do what was necessary to make them better and the kids would “let them do it and get it over with” (Boyd & Hunsberger, 1998, p. 335). Independent activities seeking to take charge of the things within the child’s control was yet another coping mechanism. The child would try to do the physical activities that he/she could master on their own.

Emotional expression was a common response to the painful procedures and usual frustrations of the hospitalization. Children recall crying, screaming and yelling as a way to deal with these events. Another form of expression mentioned was verbal expression. This included talking about their feelings or concerns. It also encompassed telling the staff when something was painful. An additional coping strategy was discussed in a limited capacity. This included the child

seeking information in order to understand their health issues or be better prepared for a procedure.

Cognitive Coping Strategies

Aside from the behavioral coping strategies, cognitive coping strategies contribute to the chronically ill child's ability to deal with repeated hospitalizations. The children in the study gave insight into their minds and how a child copes on a cognitive level. Much like the behavioral distraction, children also practice cognitive distraction in which they try to "...think about other things." Hand in hand with cognitive distraction is avoidance, where the patient just tries "not to think about it." Self control was also mentioned.

Cognitive restructuring or trying to maintain a positive outlook was an additional cognitive coping strategy. This technique seemed related to the confidence that the children placed in the hospital staff. The children realized that the doctors and nurses, as well as the hospital stay were an attempt to improve their circumstances and should therefore be viewed in the most positive way possible. Endurance was a technique that was useful. In the hospital, many events are beyond the child's control. Being able to live through an unpleasant event and look forward to its completion was seen as a helpful technique.

A final cognitive coping strategy that the children indicated as being helpful was knowledge and familiarity. Many of the children found it comforting that they knew what to expect from the familiar procedures. Familiar hospital staff and procedures contributed to this ease of mind as well. In some cases, past

negative hospital experiences actually caused the environment to be more distressful.

Dependence on Others to Cope

Evident in the Boyd and Hunsberger (1998) study was the chronically ill child's dependence on others to cope with their circumstances. Family, friends, and hospital staff all served as companions in the coping process. The hospital staff was perceived as helpful in both physical and emotional support. The children found comfort in the fact that some of the caregivers were familiar to them. Another important factor in the health professional's role was a positive attitude. The staff was seen as helpful if they provided helpful information and explanations of procedures. The children liked someone they could talk to who would listen. Additional factors such as respecting the child's privacy, being patient, gentle, and recognizing the child was a unique person with thoughts and feelings were appreciated. A positive mood and a good sense of humor were other attributes the patients found beneficial.

The children also noted actions and characteristics on the part of the staff that did not promote their coping process. Not providing adequate information was not beneficial in helping the children deal with necessary issues. In general, an attitude of insensitivity, and impatience were unhelpful. Lack of respect, and ignoring the child's need for privacy were also mentioned. Another negative factor that the children noted was the health care professional hindering the child's personal control. The final element that seems to encapsulate the overall

picture of a health care provider that does not enhance a child's coping process is not smiling.

Although health care professionals provide an important role in the process of helping a child cope with hospitalizations and chronic illness, it is the family and friends who provide the most significant roles in assisting these children in dealing with the everyday issues before them. The presence of family and friends added great comfort to the hospitalized children. Frequent visitation was considered helpful as it provided support and reassurance to the children, as well as gave them someone to talk to about their concerns of their illness. Family and friends also assisted the children in practicing some of the coping strategies, such as distraction. The children made comments such as, "Like they try to calm me down, like get my mind off it...Like they'll play a card game with me or watch like a movie together" (Boyd & Hunsberger, 1998, p. 336). In addition to the physical presence of the family and friends, the children appreciated the gifts the loved ones brought them to try to make them feel better.

The process of coping for a chronically ill child is a multi-faceted situation. The child's illness affects not only the child, but the child's family as well. Adding to the complexity of the situation, the child's family affects the child's coping strategies causing a potential for a cycle. The process model of stress and coping offers a definition that is often referenced in literature concerning families facing a child's chronic illness. The process of coping can be easily understood and applied through the use of this model.

CHRONIC ILLNESS

In focusing on issues of hospitalization and coping, there is a distinct population of children who must face these experiences on a routine basis. Due to the technological and medical advancements of the last several decades, the survival rate of children with illnesses has increased. These children are now faced with coping with a chronic illness or disability (Hostler, 1991; Rose & Thomas, 1987; Stein, 1989). According to the U.S. National Center for Health Statistics (1994), in 1992, approximately 292 million people in the United States were affected by chronic illnesses. Recent estimates indicate that 31% of children in the United States are faced with one or more chronic illnesses (Melnyk et al., 2001).

Chronic illnesses are considered the foremost health problems in our country today (Pollock, 1993). Numerous researchers have documented a substantial increase in families coping with the chronic illness of one of its members (Gilliss et al., 1989). Families are increasingly responsible as caregivers for the chronically ill. This illustrates the need for increased attention and study devoted to these family units.

Decision-Making Process

Because of the fact that today most children with chronic illnesses live into adulthood, choices concerning their health care in their lifetime are numerous. The decision-making process is an important aspect of dealing with a chronic illness. This responsibility primarily falls on the family of the ill member. These

decisions are influenced by the context of the illness and the experiences of the parents and the children (Angst & Deatrck, 1996).

The importance of the patient in the decision-making process is also acknowledged (Schmidt, 2003). This involvement allows the patient to assume increasing responsibility for their care as they mature into adults. It is advised by the American Academy of Pediatrics' committee on bioethics that children participate in decisions that are developmentally appropriate, and not be excluded from decision-making without a persuasive reason (American Academy of Pediatrics, 1995). Additionally, children should be allowed to provide agreement to care when reasonable (American Academy of Pediatrics, 1995). Failure to allow children's participation in such aspects of their treatment may hinder the child's adaptation and potentially damage their sense of self (Angst & Deatrck, 1996).

Stressors in Caring for Chronically Ill

Much research has been conducted over the last thirty years focusing on the stressors that face caring for a chronically ill or disabled child (Beresford, 1994). These studies have highlighted the problems that are inevitably involved in the process of caring for the ill child, addressing such questions as "What problems do these families show?" (Miller et al., 2000, p. 3). Some recent researchers have seen the need for a shift in the emphasis from the description of the stressors and their negative effects. Instead, an emphasis should be placed on exploring how families cope with the surmounting problems (Beresford, 1994; Miller et al., 2000).

Health Care Professional's Role

An abundance of the practical literature focuses on the health care professionals' role in assisting the patients while they are in the health care facility (Godshall, 2003). This role is greatly needed and beneficial. However, it is imminent to recognize that, in the actual lives of the families in dealing with chronic illness, life beyond the hospital exists and is extremely demanding. Providing optimal care translates into how successfully the health care professionals can assist the family and the child cope with the new challenges they face when they leave the hospital (Worthington, 1995).

Multiple Stressors

The realization that families are dealing with multiple stressors at the time a child is hospitalized highlights several questions in relation to discharge follow-up programs (Snowdon, 1995). Should the programs be attempting to solely meet the needs relative to the child's illness? Instead, should the follow-up programs expand their emphasis to include issues that the family unit may need to deal with?

Siblings

Some of the stresses that exist beyond the hospital are included in Worthington's article. He addresses several issues that siblings face when a brother or sister is suffering from a chronic illness. The siblings' lives are directly and indirectly affected by the illness. The well children may resent the time, attention or money that is designated for the sick child (Godshall, 2003). Another issue the siblings may face is the public ridicule that the sick child

receives. The well child will often be faced with the realities of being the defender of the sick sibling (Worthington, 1995).

Marital Stress

Parents' close interpersonal relationships change when their child experiences a chronic illness. "Some people draw closer, some drift away, but all relationships change" (Ray, 2002, p. 431). This observation seems consistent within the marriage relationship. Some studies have specifically addressed the marital relationship and distress resulting from dealing with a chronically ill child (Walker, Manion, & Cloutier, 1992). These studies are conflicting in their summations of whether or not the marriage relationship is necessarily unstable due to the illness of the child. There is a wealth of qualitative literature that supports the idea that the marital relationships of parents with chronically ill children indeed suffer greater instability.

Marital stress and conflict often result from a child's chronic illness (Worthington, 1995). The extensive care of the sick child diminishes the resources that the parents have to offer to the marital relationship. The result is often the renegotiation of marital roles. For example, one or both parents may change their careers or working arrangements in order to meet the special demands of the situation.

Financial Stress

Financial stress is typically high in families dealing with the chronic illness of a child. Unexpected financial burdens are placed on the parents. The problem increases when financial burdens are complicated even further because there is

less time available to work due to the care of the sick child. These burdens are often enormous for a family in this circumstance.

Parental Needs

Few studies have identified the needs of the parents after the discharge of the child from the hospital. Snowdon and Kane (1987) conducted an exploratory and descriptive study of sixteen families at a large acute care hospital in Canada. The study examined the needs of parents after the child's discharge. In order to assess these needs, the families received an at home visit within twenty-four hours following the child's discharge. Most families requested an additional follow-up visit at a later date. Telephone interviews were conducted after the home visits to assess the effectiveness of the discharge follow-up program. High levels of satisfaction were reported by the parents. All of the participating families recommended such programs.

Snowdon and Kane found that the parents expressed needs in two particular areas. First, they had a need for information. They desired information pertaining to the following areas: their child's illness, the treatment and care the child had received at the hospital, instructions on the child's care at home and prevention of recurrence of the child's illness. Several parents commented on the fact that it was beneficial to be able to ask questions that "no one in the hospital had time to answer" (Snowdon and Kane, 1987).

These interviews raise questions relating to the discharge process of patients. Are parents not receiving the information they need upon the child's discharge? Do parents have trouble communicating their needs to the hospital

staff? Are the discharge instructions based on general information that the staff perceives to be important irrespective of the parents' perceptions of their information needs? Sabbeth & Leventhal (1988) described parents' inability to effectively communicate their needs. Consequently, the needs of the parents may go unidentified if they are not adequately communicated during the child's hospitalization (Sabbeth & Leventhal, 1988).

The second need that is identified by the parents in the Snowdon and Kane study is the need for support. Families associated some perceived stress to be coming from the hospitalization experience of the ill child. These stresses included developmental delays in the sick child.

The hospitalization not only affected the sick children. Parents noted that the other children in the family were also impacted. The siblings often expressed worries or complaints of being sick themselves. The mothers were frustrated with balancing their attention between the hospitalized child and the other children.

In addition to the immediate stresses initiated by the hospitalization, the families were simultaneously experiencing other stressors. These multiple stressors intensified the overall portrait of the distressing hospital experience. There were several examples of other stress events contributing to the duress (Snowdon and Kane, 1987). One single mother was undergoing cancer treatment herself. Another single mother was raising twins, one of which had a congenital heart defect. In addition to dealing with the child's illness, she had also been recently diagnosed with muscular dystrophy. These multiple stressors illustrate that having a sick child does not take place in a vacuum. Like everything

else in this life, the trauma of dealing with an unexpected illness or tragedy occurs in the midst of the every day life stresses. These multiple stressors intensify the need for support of families undergoing such demanding times.

The necessary skills required to raise a chronically ill child are above and beyond those required for parenting a typical child. Society depends on parents to provide complex care to those chronically ill children, with virtually no additional knowledge or training compared to that of an average parent. Ray's PACC model, Parenting and Childhood Chronicity, revolves around a pie chart which includes the following aspects of parenting a child with a chronic illness: medical care, parenting plus, working the systems, parenting siblings, maintaining relationships, and keeping yourself going (Ray, 2002). These concepts were explained to the study group that consisted of 43 parents and 34 children with various chronic conditions. Through the interpretive perspective, the ideas and viewpoints of the respondents were collected. The researcher believed that understanding the families perspectives and interpretations of their circumstances was critical to understanding the health of such families.

Medical Care

Parents of chronically ill children are often expected to implement extensive medical care at home. This can be initially frightening due to their lack of expertise and training in the area. Parents estimated that an adjustment period of six months was required before they felt this aspect of the child's care became second nature (Ray, 2002). Parents noted that it was more difficult to administer care that required a struggle between the parent and child, or that caused pain to

the child. Parents also expressed that the extended family, schools and general public were frightened by the technological aspect of the child's care (Ray, 2002). Over time, parents of chronically ill children develop expertise in the care of their child, and want the healthcare providers to value their participation in the child's care (Balling & McCubbin, 2001).

Parenting Plus

This facet of the parental role is that which is typical, but increased in intensity due to the child's condition. Examples of such parenting include compensating for either delayed or non-existent skills in the child. Parents often go to great efforts to help their child reach his or her greatest potential by providing essential education such as sign language or occupational therapy. They find creative ways to promote their child's development physically, emotionally and socially. These efforts range from buying special equipment to creating social opportunities for their children to make friends.

Working the System

Parents expressed great frustration with working within the health, social service and education systems. An estimated 50% of their caregiving time was consumed by this endeavor (Ray, 2002). This effort was seen by some parents as the "...worst part of having a child with a chronic condition" (Ray, 2002, p. 428). One parent expressed, "You don't KNOW what you need. And you don't know what people have to offer" (Ray, 2002, p. 428).

Keeping Yourself Going

Parents in the PACC study explained that they kept going by "...just doing it" (Ray, 2002, p. 432). The parents were too busy with the necessary activities to sit and analyze how they persevered. It comes down to choice. One parent expressed that it was the love of her child that motivated her to continue. "You can fall apart or you can keep going. You get up in the morning and just do it. I don't know, you just do it" (Ray, 2002, p. 433).

Taking care of themselves as individuals is also an integral part of the parental role in staying healthy. Sometimes the only motivating factor in this pursuit was the thought that there would be no one to care for the child in his or her absence.

FAMILY ADAPTATION

The many stressors faced by families coping with chronic illness can easily overwhelm the members of the family. Family adjustment and adaptation can be difficult in such trying times. The attributes used to define family adaptation to chronic illnesses are considered by Julie Clawson. Clawson (1996) believes that four attributes contribute to the process of family adaptation. First, it is a process of variable stages that should be viewed over time rather than in a moment in time. Second, adaptation is composed of adaptive tasks that are considered growth responsibilities. These adaptive tasks include both instrumental and emotional components, and are used to manage the chronic illness situation. The third attribute is considered coping strategies. Coping strategies are defined as "what one does about a perceived problem in order to

bring about relief, reward, quiescence, or equilibrium” (Weisman & Worden, 1976, p. 3).

Canam (1993) has developed a list of eight tasks that provide insight into the process of adaptation to a child’s chronic illness. The list includes the following tasks: accepting the condition; managing the condition daily; meeting the normal developmental needs of the chronically ill child; meeting the normal developmental needs of the other family members; coping with the ongoing stress and crisis; assisting family members to manage feelings; educating others about the chronic condition, and establishing a support system.

Family adaptation to a child with a chronic illness is related to three interrelated components including knowledge, skills, and resources (Canam, 1993). Knowledge is the motivation and the ability to acquire and process information regarding the chronic illness (Canam, 1993; White, 1974). A parent’s ability to obtain information from the nurses and doctors would illustrate this component. Skills are considered to be the abilities used to meet the demands of the illness (White, 1974). An example of this is a parent being capable of operating an asthma machine in order to successfully medicate the asthmatic child. Resources can be physical, emotional and material (Canam, 1993; White, 1974). A simple example of a resource is finances.

When a family is faced with the challenge of dealing with a chronic illness in one of the children, adaptation is desired. Clawson (1996) concludes that if the family views the illness as a stressful event requiring ongoing family adaptation,

the family can proceed through the steps outlined; the result can be growth for the family and a sense of mastery for the family system (Clawson, 1996).

ADDITIONAL SUPPORT

In order to assist families with chronically ill children, an intergenerational support program called “Family Friends” was developed by the National Council for aging in 1984. Volunteers (ages 55 and older) are trained in the medical and psychosocial aspects of chronic illness. These volunteers commit to visiting a family’s home at least once a week. During the visits support is given through several avenues. The volunteers play with the ill child and with the siblings. In addition, supportive conversations and assistance offer some relief to the parents.

Kuehne (1989) studied how the Family Friends program in Omaha, Nebraska affected the coping strategies of the parents of chronically ill children participating in the program. Parents were given questionnaires regarding their coping skills as well as several long answer qualitative questions to determine the perceived experience offered by the Family Friends program.

The Family Friends program proved to be beneficial in a number of ways. Three of the coping strategies used by the parents showed significant differences before and after the participation in the program. Talking with professionals was reported as a coping strategy significantly less often after the participation in the program. Another related coping strategy that was reported less often after the group participation is that of talking to a friend. Although these categories declined, the frequency of talking with the Family Friend volunteer as a coping

strategy from the first to second measured time increased significantly. Other differences were found in the coping behavior prior to the program and after the program. Parents reported hiding their feelings more often at the second time studied. In addition, after participation in the Family Friends program, the parents reported fewer attempts to relax as a coping strategy.

In an effort to find information available in addition to the literature base, a search of the Internet revealed some interesting and creative approaches to dealing with the coping skills of ill or hospitalized children. Several programs were noted that seemed to offer unique perspectives. The Starbright Foundation, a Los Angeles based non-profit group is chaired by Steven Spielberg. The foundation's mission is to improve the emotional resilience of children with chronic illnesses such as leukemia and cystic fibrosis. This foundation, with the help of consulting psychologists, produces games and videos to teach children about their illnesses. The Starbright Foundation seeks to help kids cope with stressors associated with repeated hospitalizations, chronic pain, or rigid treatment schedules (Sleek, 1999). "Starbright World" is another effort by the foundation to aid children in their efforts to cope with their illnesses. This service is a private online hospital-based network, including chat rooms, videoconferencing, and other interactive services. These interactive efforts allow the children to communicate with other peers and support one another as they struggle with similar illnesses and related issues.

SUMMARY

The issues that families face when coping with a child with a chronic illness are numerous. Through research on the subject, it is evident that the families face multi-faceted challenges. These include issues that relate to the family as a unit as well as to the individuals and the various relationships within the family. Coping strategies and adaptation skills can be enhanced by the education of the families, health care professionals, and social support groups interacting with the families.

CHAPTER III

METHODOLOGY

The purpose of this study was to explore the realities of everyday life and challenges that face a family when a child has a chronic illness. Qualitative investigation was practiced in this study in an effort to better understand the multiple realities that a family experiences when undergoing such stressful and life-altering events. Through the use of interviews and observations, the researcher was able to gather data and discover emergent themes throughout the duration of the study.

RESEARCH DESIGN

The design for this study was based on the qualitative method of the case study. Lincoln and Guba (1985) describe the case study as “a snapshot of reality” or a “slice of life” (p. 214). Following the naturalistic paradigm, the case study adheres to three essential purposes (Lincoln & Guba, 1985). First, it provides “thick description” or detail that is essential in the transferability of the happenings to the reader’s own experiences. The writing style is almost that of a novel, depicting the relationships and complexities of the context and content in such a compelling manner that the reader feels as if he or she becomes an integral part of the study. The second purpose is the revelation of the multiple realities that are inherent in qualitative research. This includes not only the multifaceted realities of the subjects, but the interactions of the respondents and the investigator, as well as the reality of the researcher’s values and the values of the context that he or she examines. The case report serves a final purpose of

communicating to the reader in such a lifelike manner that the reader senses a feeling of having been a participant in the situation or experience in a previous time. Erlandson, et al. (1993) expresses that a well-written case study is a work of art that requires the audience to interact with the setting both emotionally and cognitively.

SUBJECTS

Respondents for this case study included the members of three families that have experienced the chronic illness of a child. Through the use of purposive sampling, the researcher attempted to engage in the interview process with individuals and families who were able to contribute to the understanding of the phenomenon being studied. The respondents' ability to add to new constructions of the reality or give further insight into the existing premises was considered when choosing the individuals to participate. Erlandson, et al. (1993) describe a good respondent as one who understands the culture and can reflect and relate it to the researcher in an understandable manner.

The families chosen were those who required on going care for the ill child, including possible repeated hospitalizations. The children in poor health ranged in age and type of illness. The families also varied in relation to their family dynamics and socio-economic status. The researcher initially met the families through volunteer work at a children's hospital. The families willingly agreed to participate in the research study described by the investigator. Each family was originally interviewed as a whole. Later, the members were

interviewed individually. Observations occurred throughout the process of the study.

INSTRUMENTS

The primary instrument for this research endeavor was the human instrument, or researcher. Lincoln and Guba (1985) believe that “if you want people to understand better than they otherwise might, provide them with information in the form in which they usually experience it” (p. 120). The human instrument is considered the choice instrument of research in the naturalistic inquiry for the following reasons (Lincoln & Guba, 1985):

1. The human instrument is responsive and can interact with the personal and environmental situation.
2. The human instrument is adaptable and can gather information at multiple levels and about multiple factors at one time.
3. The human instrument is capable of viewing the phenomenon and its context a holistic manner.
4. The human instrument can expand the knowledge base through the collection of data.
5. The human instrument can process data immediately as it is encountered and respond or question the new information.
6. The human instrument’s conceptual abilities allow opportunities for clarification, correction and summarization from the respondent.
7. The human instrument can explore atypical responses in order to offer a more in-depth understanding of the phenomenon.

Several advantages of the case study method, using the human instrument, are suggested by Lincoln and Guba (1985). Thick description and detail are advantageous in fostering the transferability of the findings. In addition, the human instrument is responsive to the multiple realities of particular contexts or situations. Also seen as a benefit of the case study is the ability of the case report to reach its readers to a greater extent than a traditional study method. The reader will ideally be able to relate and apply their own experiences and feelings when reading the study, and therefore be able to benefit from applying its realities to their own lives.

PROCEDURES

The following steps were taken in order to complete this naturalistic inquiry:

1. The researcher examined literature for information relating to families coping in situations with chronically ill children.
2. The researcher conducted unstructured and semi-structured interviews with the participants. An initial family interview was followed by individual interviews with the participants. The informal interviews allowed the participants to dialogue with the researcher and answer embedded questions.
3. The researcher conducted observations of the participants in their home setting or a setting chosen by the participants.
4. The researcher examined relevant documents or records offered by the participants including: informative handouts,

photographs, teacher's letters, sibling letters, hospital bills, drawings, and e-mails.

ANALYSIS OF DATA

The analysis of the data in a naturalistic study initiates at the beginning of the project. The collection and the analysis of the data are entwined as themes and theories emerge throughout the process of the study (Erlandson et al., 1993). The goal of the researcher is to bring order and meaning to the data collected. In order to accomplish this structure, the comparative method (Lincoln & Guba, 1985) was employed. In this process, the data was broken down into the smallest independent units possible, and then organized into emerging categories.

In order to assure trustworthiness in this naturalistic study, six techniques were practiced (Lincoln & Guba, 1985).

1. Prolonged engagement promoted credibility by enabling the researcher to learn more about the environment of the participants, and to build trust with the respondents.
2. Triangulation of the data fostered credibility by offering multiple sources, methods, and theories.
3. Peer debriefing contributed to the credibility by the researcher seeking the input of a third party who had a general understanding of the research.

4. Referential adequacy materials improved the credibility of the study by offering background materials that supported the meaning and data analysis of the study.
5. Thick description offered transferability to the study by providing details that allowed the reader to apply the information to his or her own experiences.
6. Member checking provided credibility by offering opportunities for the respondents to check the information, interpretations, and categories suggested by the researcher.

SUMMARY

This research project was conducted using the method of the case study in an effort to allow the reader to experience the everyday realities, concerns, and opinions of the participants in an in-depth manner. The findings of this research study give insight into the complex circumstances involved in the lives of families coping with a child suffering from a chronic illness. Themes were identified from the information and data collected from both the observations and interactions with the families. These themes were considered in context with the literature review on the topic. An analysis and discussion of the topic and its emergent themes were presented. The results of this study provide parents, children, medical staff, and educators with additional information about how families cope with chronic illness in a child.

CHAPTER IV

RESULTS

The depiction portrayed on the following pages is one of unsung heroes. The people who have shared for the sake of this research have given freely of their valuable time and strained emotional resources. They have been willing to openly and candidly share their experiences, heartbreaks, trials and tribulations in an effort to help others who may walk in their footsteps. The stories shared in this dissertation are based on families who endure their child suffering from a chronic illness. It is the tale of unexpected trauma that families experience.

The individuals who face the challenges of dealing with a child suffering from a chronic illness develop skills and coping techniques that many people will never possess. They face numerous obstacles of many sorts as they walk through this life. As a researcher observing and learning from these individuals, I felt blessed to have been included in the process and sharing of the lives and stories of the participants. I have been impacted by their perseverance and amazed at the character of the individuals that persisted despite the numerous challenges.

This research topic is very personal and emotional. In an attempt to create a vicarious experience for the reader, I will use the first person in this section of the paper. It is hoped that the reader, you, will begin to experience the reality that I, the researcher, was privileged to participate in.

RICHARDS FAMILY

“Go Away!” were the words on the first mat on the sidewalk as I approached the Richards’ residence. Their home was located in a well-to-do suburban neighborhood on the outskirts of Houston. The Clear Lake area seemed a likely fit for an engineer seeking to raise a family in the typical suburban fashion. The well-kept house resembled that of every other in the neighborhood: a manicured yard, family SUV, and sidewalk to the nearby park. Yet, behind the front door existed an environment and experience very unique to this family. As I approached the door, only a few steps later, I then encountered your typical “Welcome” mat that one would expect.

I felt privileged to enter into the domain of my new research participants. The entryway and formal living and dining area looked as if perhaps many others do; hardly lived in, tidy and well decorated. As I passed into the next room, I began to feel the reality of this family’s experience. The informal living area consisted of a navy conservative couch and bookshelves filled to the rim with books and videos lining the walls. The remainder of the room was converted into what appeared almost like a kindergarten classroom with various work centers. From the mantle before me, hung a huge thermometer replica. There was a computer with enlarged letters on the keyboard. To the right of the computer was a piece of equipment I later learned was a CCTV, or closed circuit television. This screen is used to magnify reading materials for people who are visually challenged. The kitchen bar was to the right, and divided the living area from the

kitchen. Windows in the back right-hand corner surrounded a breakfast nook. A small round kitchen table was covered with a flowered tablecloth.

The Richards' family members are in many ways like other American families. Yet, in other ways, these individuals have experienced hardships and obstacles that most are fortunate to bypass. We all sat around the informal breakfast table for our first meeting. Ten-year-old Maggie is the child in this family that suffers from a chronic illness. Maggie, born with Joubert Syndrome, sat in her plastic covered chair in case her pull-up leaked. Her older sister, Megan sat next to her, obviously reluctant to be a part of the family interview. Next at the small round table, was the mother's live-in boyfriend and fellow caregiver to the girls, Tim. Alice, the mother of the two young girls sat to my immediate left. The only family member missing at this meeting was the father, Fred. Another meeting was to be arranged with the girls' father on a separate occasion.

As I explained the nature of my study to this family, it was apparent that Maggie's illness was an open topic of discussion in the family. In reference to Joubert Syndrome, Maggie interjected, "It doesn't mind me." Maggie has suffered a form of cancer, and is currently officially in remission. Maggie is legally blind, and yet she carefully took notes alongside me throughout the interview. She was proud to point out to the rest of us, "My handwriting is really small now." She had obviously been working on this skill.

Maggie's mother Alice began an overview of the illnesses and disabilities that Maggie endured as we all listened. I would ask occasional questions to

clarify my understanding. The other participants would at times interject their opinions into her discourse. Alice was very knowledgeable about her daughter's conditions, which became even more apparent as our interactions progressed.

Alice gave me a description of Joubert Syndrome, and instructed me to research it on an Internet site to better understand the illness. On the site of the Joubert Syndrome Foundation, I discovered that the illness is a very rare genetic disorder. Both parents carry a recessive gene and have a one in four chance of having another child that suffers from the same syndrome. In fact, Maggie's brother suffered and died from complications of Joubert Syndrome.

Alice explained that Maggie suffered from kidney failure, which is often associated with the syndrome. The kidney problems were diagnosed two years ago, in February. The problems progressed rapidly and Maggie suffered renal failure less than one year later. At that time, her father was going to donate a kidney. However, that plan did not transpire, and Alice, the mother, ended up donating her kidney to her daughter.

One of the prominent topics that surfaced a number of times, was that of nutrition. Due to Maggie's illness, her nutrition was very important to monitor. Her kidney was unable to process many foods. These dietary issues were difficult for the family to manage at times. Maggie was often very reluctant to follow the correct eating plan. At our meeting, Maggie gladly announced, "I can have almost anything now!"

Tim and Alice jointly described the peritoneal dialysis, required for Madison's kidney condition, to me. This process required an hour and a half for

each procedure; the at-home care took place five times a day. This sterile process took place from seven am until midnight for over a three week time frame. Tim maintained, "We had no life during this time." The doctors praised their efforts and success with the at home dialysis, because Maggie went through the process without infection.

As we discussed the lengthy and stressful process of the peritoneal dialysis, big sister, Megan balanced a spoon on her nose at the table. The siblings then ensued in a typical sibling argument over the pronunciation of the word tomato. It was refreshing to see the girls engaging in typical sibling activity.

The kidney transplant was finally scheduled for February 11, 2003. Alice self-sacrificially donated her kidney to her daughter. Due to complications of several other scheduled kidney donations, the transplant did not transpire until March 4, 2003. As it turned out, Alice did not bounce back from the transplant as easily as she had expected. She stated that she delivered three kids vaginally, only to deliver a kidney by C-section.

The recovery was a slow process. Tim served as a support for the family in addition to the girl's dad, Fred, and other family members. Alice was in the hospital for five days after the surgery. Following the surgery, an aid came to the house to assist for a few weeks. Alice is thankful that they had excellent health insurance that allowed for such benefits. Maggie was unable to return to school due to her immunities being suppressed. She could easily acquire an illness if exposed.

It was at this time that Maggie began to home school. She was on a large number of medications, which the family refers to as “meds”. Maggie felt these medications tasted better than the ones previous to the transplant. That fact encouraged Maggie’s compliance with her prescription routine. Compliance to her medications had been an issue in the past. Maggie is known to have temper tantrums and refuse to take her meds. This causes a great deal of stress as the family is seeking to make her life as positive as possible.

Upon returning to school after the transplant, Maggie began refusing to eat at school. Her mother could not initially understand. She took her to the doctor to no avail. However, by the end of June, Maggie was in the hospital with pain in her belly. After a few days stay, Maggie was sent home only to return shortly with severe abdominal pain. At this time, she was unable to hold any food down and had become dehydrated. Her creatine levels had risen, threatening her new kidney. A couple of weeks later, Maggie was diagnosed with PTLN (Post Transplant Lympho Proliferative Disease). Maggie had contracted the Epstein-Barr Virus, which was very serious due to her immunities being suppressed. In fact, the medications they were giving her were too high a level of anti-rejection drugs. Because of her medical instability, her mom said, “I couldn’t kiss her or she would get my virus.” This EBV then turned into a cancerous lymphoma that threatened her life. A detailed explanation of B cells was relayed in an effort to help me understand Maggie’s condition at the time. Once again, I struggled to follow the unfamiliar medical terminology and conditions. I can only imagine the

frustration and despair when a doctor informs you about your own child's unknown condition.

It was very clear that Maggie's life was on the line at that time. She was placed in the pediatric intensive care unit, PICU. Tim remembered all the "tubes hanging out of her." There was a point at which he refused to go into the PICU to visit her because of his own emotional state. Originally, he visited Maggie in the PICU; once they put the breathing tube down her throat, he could not visit the bedside any longer. He felt that Maggie was going to die at that point. Tim expressed that he was unable to talk to anyone about his feelings at that point because his perspective would have been horrid.

He also indicated his lack of expertise in the medical field and stated, "I'm not a doctor. I don't have any medical experience. I couldn't understand any of what they were talking about, except from what they explained." He shared his lack of answers, "I didn't know what to do." Tim felt that it was a miracle that she survived. His uncertainty continued with the honesty of "maybe I'm not strong enough to be in this situation." He believed he wasn't capable of being whatever support he needed to be in a number of different aspects. When things get serious, he stated he works under a non-emotional level, and just does the job.

Other than going into the PICU, Tim was very involved in Maggie's care even to the point of replacing her central line (tube leading directly to the heart) fluids, and serving as the primary person administering her peritoneal dialysis, with Alice's assistance. "I just took it on as this is something that has to be done, and I did it. I didn't attach any emotional baggage to it. I just did it."

Tim felt that he has served as a physical support, but not an emotional support. He believed that the added strain of Maggie's condition made issues that were previously insignificant, in regards to his and Alice's relationship, more disruptive.

Tim viewed Maggie's care as the paramount issue. "Out of necessity for her survival, everybody had to do their part," Tim recognized. Although there were relational struggles, Maggie's care took precedence, and he realized she needed the support system around to complete her care. Tim recognized that Alice's perspective appeared to be that if he wasn't around, she could have gotten professional care. He acknowledged that Alice is very intelligent and resourceful, and would have figured an alternative way to get the necessary help. There were times when the relationship aspect of this partnership was seen as a "roller coaster". Perhaps the added stress of the relationship had added more stress than assistance, he feared.

When Maggie was in the hospital, Alice tended to her daughter's care. Tim stated, "She didn't trust or want the nurses to do just about anything." The care of her daughter needed to be done in a certain manner, and she was often dissatisfied with the performance of the nursing staff. From Tim's perspective, it seemed more of a control issue, to the point where she wouldn't allow anyone to do anything.

Tim asserted his strengths in many areas. However, admittedly, death was not one of those strengths. This caused additional relational problems between Tim and Alice; she felt a lack of support at the time she needed it most.

Retrospectively, Tim realized that she felt a lack of support and love; he still maintained that he could not face the issue of death.

Tim offered his support at that time by helping in other ways. He would pick up the big sister, Megan, from school every day, and then drive her one hour to the hospital. She would often do her homework at the hospital. Tim would wait in the waiting area, but just not visit the bedside. When it was time to leave, Alice would stay at the hospital; Megan would either go home with her father, or Tim would take her back to the house with him.

Tim felt that the most difficult time for the family was when Maggie was in and out of the hospital due to abdomen lesions. Maggie was in and out of the hospital almost every other week. One hospital stay lasted for eight weeks due to the lesions in her intestines. The septic bacteria resulting from the lesions could have been lethal. She also had a form of cancer, and needed chemotherapy. "It was non-stop. There was a constant barrage of circumstances threatening Maggie's life," according to Tim. After the hospital stay, a home health aid came to the house 5 times a week, and then 3 times a week for a number of weeks.

Tim's Interview

Tim answered the door the first time I arrived at the Richards residence. He greeted me with only a few words and seemed rather standoffish. He is a fit man with long dark hair pulled back in a ponytail. Tim is the live-in boyfriend of Maggie's mom. He has been an integral part of the care giving team for ten-year-old Maggie and her twelve-year-old sister, Megan, for a while now. Later, as I began to get to know Tim, he allowed me to enter into his thoughts, and was

forthcoming with his opinions. His summations were insightful, as he interjected ideas throughout our time together. It was very clear that Tim respected his girlfriend for her efforts with her children and her inner strength as a woman.

As far as outside sources of entertainment or coping resources, Tim spends a great deal of time involved in an extreme sport called Ultimate. The sport combines soccer and football skills and is played with a high-tech disc. From both Tim's and Alice's perspectives, it was clear that his time commitment to this sport had at times strained their relationship.

He stated that in the beginning of his relationship with Alice, they would take the kids to and from school on their bikes together everyday, as well as going camping and rock-climbing with the girls. Alice took vacation in order to spend more time caring for the girls. Tim was out of work at that time so it allowed them time to spend together.

When Maggie's problems arose, Tim felt it created confusion as to the various roles each played. He felt an issue that arose was the justifiability of other activities verses abandonment. What originally began as debates escalated over time. He stated that for the first eight months or so he was not involved with the care of the children. Once he moved into the house, he said it was still several months before he was much help. He felt this was because he didn't know how to get involved. There was a reluctance to just "take charge".

Tim thought that it was beneficial to have the teachers come to the house to home school Maggie. He indicated that more time with the teachers would have been helpful for Maggie. From his perspective, one teacher in particular did

little teaching, but simply filled the role of babysitting. Tim related Alice's difficulties in getting the educators to understand some of Maggie's special needs and requirements. He offered several examples of skills Alice was advocating for her child, including Maggie's necessity to learn to read Braille or use an abacus for her potential total loss of eyesight. The school insisted that Maggie use the eyesight she did possess with devices such as a CCTV or a magnifier. Tim expressed, "There is nothing she could do to make them understand that Maggie needed a certain level of care that she wasn't getting." Tim doesn't pretend to know what's best for Maggie in this area. He said his perspective is one of experience of having worked with machines, but never of working with kids with disabilities.

Alice's Interview

Alice's determination and love for her children is evident through observation of her interaction with her children and their daily activities. This mother who previously worked full time outside the home, has been serving as a full-time care-giver and advocate for her children and their special needs.

As for finances, the Richards family is fortunate compared to many families that care for a chronically ill child. Unfortunately, the reason behind the lack of financial pressure is due to a legal settlement resulting from a suit involving the death of Alice's son. He suffered from the same syndrome as her daughter, but the severity was much more extensive. The money is not enough to last a lifetime, but at least helps the family get through this time period. There is also financial security resulting from adequate health insurance. Alice's

company had a “leave donation” policy where fellow employees could donate their vacation time to those in need. The generosity of others assisted her family through this program.

With respect to resources and assistance, Alice has some support, but seems self-reliant in many ways. She shared that her family was close-knit, but that they see each other socially rather than “exchanging services”. Her mother kept Maggie one night, but was afraid to take care of her. The balance of the responsibility of her children’s care is currently toggled between herself, her ex-husband and her boyfriend. Alice has been able to work part-time during the worst part of Maggie’s illness. Her ex-husband worked full-time. Her live-in boyfriend had been out of work, but assisted a great deal with the children in their daily activities. She elaborated, “Tim and my both not working allowed us to all three ‘protect’ Fred’s job by not letting the kids’ needs interfere with his need to be at work.” Alice believed that it took three people to raise two kids in this situation.

The repeated and lengthy hospitalizations took its toll on the Richards family. Alice spent all week at the hospital. On the weekends, she would go home at night when relieved by her ex-husband, Fred. She stated that the hospital room felt like a “cage” or “jail”. She felt that she couldn’t leave the room, due to her lack of trust in the nursing care. Alice related that there was “nothing private about it,” referring to the intrusion of all kinds of people, at all hours, without knocking. She recalled a plethora of details including four a.m. blood draws, aids visiting the room to take vital signs every four hours, residents

completing rounds for their patients at seven a.m. To see the “real doctors” was another story. She did not know when they would come; she had to drop everything and deal with them whenever they arrived.

Alice expressed, “Here’s a frustration of mine.” Due to the two-week shifts, Maggie received treatment from a different nephrologist every two weeks. The first doctor failed to identify Maggie’s problem due to its rarity. Maggie declared, “Thanks to God I have an immune system now. But, I keep it away from my kidney.”

She felt the doctors and nurses never truly understood how sick she was of the hospital. She would take an occasional walk off the premises to a nearby shopping area. There was a “war inside of me wanting to take care of my child and at the same time not wanting to be there.” Alice contrasted the “mommy part of me” and other part of her praying, “please God, don’t make me go through this again.” There were times when she felt that she couldn’t stay at the hospital another night. She realizes that some people, including her boyfriend, think she does too much for Maggie. She offers no excuses.

Alice recalled Maggie being sick in bed for weeks connected to an IV pole. The challenge of entertaining her and taking care of her was extremely stressful. The hospital is also a very expensive place to live, according to Alice. The meals are expensive; the cell phone bills increase; parking can also be very expensive. When arriving home, one of Alice’s e-mails to her friends and family offered, “Life at home is so much more stimulating and interesting and fun...and relaxing and enjoyable, and we are so very glad to be home. We can’t exactly go too far or too

often because of her dependency on her IV fluids and feeds, but this is so much better than the hospital. Please pray that all will go well, and that Maggie won't get sick, and of course, that she will fully recover eventually."

When questioned about the things that seemed to assist Alice in getting through the difficult times and the hospitalization, she referred to her long time friend who would come to the hospital every night and bring her food and a movie. She felt that movies were an effective escape from her problems. Mexican food was her special treat. The knowledge that he would be there on a regular basis helped Alice more than anything she could recall.

As for outside resources, and formal support systems, Alice used the list of services posted through the Joubert Syndrome Foundation. She could post questions for other members, and get a response from them. This service was the only formal support system that Alice was involved with other than the counseling she received after Maggie's diagnosis of blindness. She believed the counseling was helpful due to the non-judgmental environment.

Alice communicated with family and friends via email to update them on Maggie's condition. This avenue of communication was exercised largely in part due to time and energy limitations. It prevented her from having to reiterate all the facts over and over again to various people. Alice kept copies of the emails and shared them with me for the research. The writings are very telling and informative and give the reader a feel for the emotional attitudes at various stages of the experiences. Closing each e-mail is a mother's compelling request and appreciation for prayers for her daughter's complete recovery and cure.

Alice shared with me an e-mail that was typed in response to an internet question by another mother debating having more children after having one with the syndrome both her daughter and her son have suffered from. I have included the letter to capture a piece of the emotional picture that has been presented to me.

My first daughter did not have any diagnosed disability, and it was easy to just sit back and watch her develop and grow with very little intervention on my part. We just played. She was a little difficult as an infant because she never slept and wanted to be held constantly, but she was my first, so I could deal with it.

Then I had Maggie, now 11. She was first diagnosed with Optic Nerve Hypoplasia, and then Lebers Congenital Amaurosis, and was not given the correct diagnosis until after my son was born. Maggie has always been a joy (in spite of her issues) and really not all that difficult to care for on a day-to-day basis as a baby anyway, especially compared with my older daughter. I remember when she was first diagnosed with blindness at 4 months old, my grandmother's first words were to ask me if I were going to have my tubes tied. I was livid. I thought, "nobody has the right to tell me that I'm not good enough to bear more children!" and, "my child is perfect just the way she is!", and "I deserve to have all the children I want!" I also thought that once I had gotten used to the visual impairment, it wasn't so bad, and certainly the joy of having my

children outweighed the inconveniences associated with the visual impairment, slight physical disability, and dealing with special education.

As it turns out, Maggie is among the higher functioning of the children with Joubert Syndrome in terms of cognition and language (but she has more recently had renal failure and cancer, too). Over time, I learned how much time and money would be spent in therapies, and how difficult it would be to advocate for services from the school – all necessary because she wasn't going to grow and develop to her potential with no intervention from me. I had always wanted three children and purposefully chose to have a third, even knowing that I could have another one "like Maggie".

After my son was born, I learned just how hard life can be. He was nothing like Maggie. He was deaf/blind, had severe physical and mental disabilities, and was chronically ill (and he eventually died). Still, I loved my son just as much as I do my daughters, and I am truly thankful I had him and appreciative of the effect he had on my life. I miss him dearly. I could never be sorry I had him. I don't think I could ever answer the question "would you have had the third if you knew it could be that difficult?" Yes - I would not be me and have learned so much without my son, and by the way, he was well cared for and didn't know he was missing anything or different from anyone else. No - missing him is horrible.

After him, I did tie my tubes. Not because I didn't think I deserved only what I had and no more, but because I could not responsibly/financially care for more children, especially children with chronic medical problems. I wished after my son died that I could have had another. I had the time and money (but no husband then!) to care for another, and I would so love the opportunity to watch another child grow and mature "on their own" with no intervention from me - like with my first daughter. But I'm older now (40), still very busy caring for Maggie while she is recovering from kidney failure and cancer, and I'm down to one kidney myself! Again, it probably wouldn't be responsible for me to have another in my situation, unless I found a very rich man who could support me and my kids - and hire a fulltime caregiver! Hah!

Adopting is an option - I think it is a wonderful way to grow your family and help children and I truly respect those who chose to adopt. It's not for everyone. You have to make sure you can love that child like your own, whether you later have your own or not. Everyone that I've ever actually met that has adopted has told me that they have easily learned to love that child as their own.

It really is a very personal thing - the decision whether to have another child. Your heart is the only thing that will give you the "right" answer.

You can't rely on other people's ideas about what is right and wrong and what you can and cannot do. All you can do is choose - and then choose not to be conflicted - and then love that child the best way you know how, regardless of how they turn out to be.

After I had my son, my grandmother had a very special place in her heart for him, as did everyone in my family. We all miss him. Maggie, also, commands a very special place in our family. I couldn't imagine life without my son when I had him, and I was devastated when I lost him, and lost for a while not knowing what to do with myself. I couldn't imagine life without Maggie, either, in spite of the difficulties we've had. I wouldn't change having had either one of them. It's just not something you regret, ever.

Faith. Love. Commitment. And through it all - have that for your spouse. Good luck.

When speaking of the loss of her son, Alice revealed that a certain amount of you dies when your child dies.

Alice's love for her children is evident in her pursuit of their best interests. She focuses on the positive aspects and abilities of the kids, while at the same time is an extreme advocate for assisting in their areas of weakness. As Alice explained the various avenues she pursued in order for Maggie to receive adequate services from the schools, I was amazed at her persistence and at the number of obstacles that were presented. The school jargon was even different

than that an average parent would know. There were ARD meetings, and IEP's (individual education plans), CCTV's and orientation mobility services. There were special needs for the visually impaired. At every turn, I found myself asking definitions in order to clarify my understanding of the situation. At one point, she related a story, and stated, "They used this as an opportunity to deny services." It is my belief that many parents would give up when faced with the number of hurdles that the school system placed before the family in order for the child to be assisted with her special needs.

Alice recognizes the extreme time commitment that is involved in Maggie's care. While this is true, she also makes an effort to maintain as much normalcy as possible in her other daughter, Megan's, life. Alice shared that there was a time when Megan stated, "I know you love Maggie more than me." Alice sat down with her daughter and explained that she loved both girls. Alice tries to make special time with Megan to take her to movies, or conferences, or work together on projects. Time is a very limited commodity in this household. On the whole, Alice feels that Megan has handled the stresses better than the remainder of the family. She referred to her eldest daughter as self-reliant, responsible, and very understanding.

Megan's Interview

Megan was energetic and confident as we set out to the destination for her interview; she wanted to take me to a nearby neighborhood park. We walked on the sidewalk along a green bayou. Suburban houses lined both sides of the bayou with cul-de-sacs backing up to the waterfront property. Megan wore long

jeans and was barefoot. The ground was hot and she walked briskly to avoid blisters.

The park was further than I imagined. When we arrived, there were kids playing on the basketball court; a boy was climbing and jumping from the top of the play equipment; there was a pool that would open soon for the summer. We chose a bench out of the sun in order to stay cool. I noticed Megan's numerous colorful bracelets and sports t-shirt. Her long brown hair reached to her waist; eyeglasses complemented her hazel-gray-green eyes. She appeared somewhat of a tomboy. Megan described herself as "half punk, half hippie, and half gothic." She will not wear a dress or anything pink, no frills, and prefers no mini-skirts. Indeed, she proclaimed that she is a tomboy too.

Along our walk to the park, I commented that some siblings of kids with illnesses feel that they don't get enough attention; Megan replied with certainty that she didn't want attention. I found it interesting that although Megan claimed to desire no attention, she was very enthusiastic about giving me numerous details about herself as an individual.

The preteen described herself as a fox. She feels she is sometimes patient, sometimes impatient. She has mood swings, although not as big as Maggie's mood swings. She is totally happy when she is with her friends. She contrasted her time at home where she is "very to myself" with her school time where she "talks a whole lot". She commented that at home everyone is doing his or her own activity. Her sister is doing her homework; her mom is working; and Tim is on the computer. There is really no one to talk to, as she perceives it.

Both girls agree that they spend little time together. Megan tends to either spend time in her room with her own activities, such as drawing or writing, or she spends time with her friends. After a quick hello, she goes and does her “own thing”. The only time the sisters converse at length is at dinner. Megan does help Maggie with her homework sometimes. Her reasoning behind this is that her mother gives her a dollar, and “every penny counts”. She smiled.

Megan is very specific when asked the age split between the girls, twenty-two months. Megan described her sister, Maggie, as sweet, nice, and caring. She commented on Maggie’s mood swings and temper tantrums. She observed that her parents handle the tantrums “sorta opposite”. Her mother takes Maggie to the other room and offers her something she likes if she will stop the behavior. Her father, on the other hand, takes something away if she continues the behavior. Megan says that she scoffs and tells her sister to “stop it”. She concluded that nothing helps.

Megan enjoys drawing. She said that she usually scribbles when she is mad. Megan shared, “I’ve never drawn anything about what happened with Maggie; I just have a memory there.” She shared that she has drawn a picture about her life, but that she doesn’t show it to anyone but her closest friend, who she considers her sister. These girls are the kinds of friends that tell each other everything. Megan spent a good portion of our time talking about her various friends and their relationships.

When talking about the time Maggie was in the hospital, she said that it was tough doing her homework. She usually completed her studies at the

hospital. She described it as “sorta annoying going back and forth. Right when I get home, I get in the car and go to the hospital, stay a couple of hours, and then come back home.” Her mom’s boyfriend, Tim, would drive her back and forth and stay with her at the house when her mom was at the hospital overnight. When Maggie was not in the hospital, Megan’s normal routine would be to get out of school, walk home, do her homework, play the tuba, and then watch a movie as a family in the evening.

Megan would call her mom’s cell phone at the hospital every night. Referring to her sister’s hospitalization, she reminisced it was “creepy seeing her with all those needles stuck in her.” When Maggie was in the pediatric intensive care unit (PICU), Megan said it “sorta freaked me out seeing her with a tube in her for breathing.” After her mother’s surgery to donate her sister a kidney, Megan remembered visiting her mother and that her mom looked pale. After the transplant, Megan was always with Tim while her father took care of her sister. Her mom was alone in the hospital.

Megan recounted the family’s confusion when Maggie was first diagnosed with the unusual type of cancer. None of them had ever heard of anything like it, nor did they know what to do about it. Megan said that she had “no clue” what was going on, and that her mother did not talk about the details often. Neither did Megan ask many questions of her mother. She stated that she did not mind not knowing what was going on; it didn’t bother her. Megan worried about her sister when she was sick; but when she was not sick, it didn’t concern her.

Megan recalled that some time after her cat died, she wanted to stay home. She remembered that she stayed home after her brother had passed away also. Her cat had been her best friend; she confided everything to this special friend. She felt this should warrant skipping school as well. She buried the cat in the back yard along with some of her dead frogs. Megan laughed at trying to get permission to stay home from school following her cat's death, and mentioned her brother as an aside. She went on to describe the importance of the cat and did not elaborate about her feelings surrounding her younger brother's death. She then added advice for friends, "a friend could help me and families like mine by just being there to talk to."

As for other obstacles in the family due to Maggie's condition, Megan only mentioned that Maggie's reluctance to take her medicines in the beginning made them late in the mornings. She does not feel that her sister's illness has affected her relationship with her parents.

When asked about her dad, Megan commented that she felt that Tim and her dad "put up with each other because of me and Maggie." The question was not geared to a specific topic. It was interesting that the twelve-year-old offered this as her conclusion. She noted that when everyone was at the hospital together it was too quiet. She feels that her parents get along really well. When it is just her four family members, she recalled activities such as playing cards.

Megan allowed me into her "fox-hole" room when we returned to the house. After ducking through the beaded doorway, I noticed the "jolly roger", skull and cross-bones, on the ceiling above her bed. Her surroundings reflect her

affinity for pirates and medieval characters. She will soon host a Lord of the Rings party to watch the trilogy with her friends. An assortment of items brings out the many aspects of Megan's personality. There is a collection of horses, a drawing of Garfield, a kimono from a friend of her fathers, a softball bat, and on the floor, a mat of colored squares. Megan concluded that one word for her would be "laid back". Indeed, on the surface, she appeared to handle the many complications of her life in stride. After all, that is the life she has known to be normal.

Maggie's Interview

The day I arrived to interview Maggie, Tim answered the door and informed me we needed to be very quiet since Maggie's mother was trying to take a nap. It was 3:30 in the afternoon; Maggie had just gotten home from the public school she attends. As I went to the kitchen table to wait for Maggie, I noticed the Happy Birthday banner hanging from the mantle in the living area.

Maggie was in the bathroom and joined me at the table within a few minutes. She was wearing a t-shirt and cotton pants. I discovered later that she was no longer wearing pull-ups as underwear; she proudly replaced the pull-ups with panties. It is apparent from Maggie's appearance, particularly her eyes, that she has some sort of disability. Her shoulder length brown hair surrounds and complements her round face. She looked tired from a full day at school, but was pleasant and funny throughout the interview. Towards the end, she rubbed her eyes and rested her face in her hands indicating we had reached her energy limits.

Maggie was quick to explain, “Joubert Syndrome is a rare disorder.” She elaborated and included that it could cause other dysfunctions of the brain and dyslexia, which she did not have. She added that her brother Ken, who died, did have some of those complications.

I was amazed at Maggie’s vocabulary. It seemed somewhat unexpected since her speech is very deliberate and slow, and her eyes jiggle and move as she sits before you. She exudes a beauty in her humor and pride as she speaks honestly and confidently about herself and her experiences. She talked to me about how her mother was her aid at summer camp, and added that her mother would be a really good homebound teacher if she so desired.

Maggie attended various camps throughout the summer. She described several that she remembered, including one about the human machine and one where she learned about magnets attracting and repelling. She also attended a summer camp for the visually impaired and blind. She said, “They put me in life skills. That’s the things that you have to do everyday.” She learned to clean up and set the table more often. She also made two noodle necklaces, one for herself and one for her sister. This attitude of sharing reminded me of the kind heart that Maggie’s family described she possessed.

Alice had attended several of the summer camps with Maggie, since some of the camps did not offer the assistance her daughter would need. Alice mentioned in her recent e-mail that she had learned a lot about Maggie’s classroom behaviors by serving as her aid in the summer classes. This experience will help her advocate for the assistance her daughter needs in

school. It also gave her insight into some of Maggie's behaviors and lack of listening skills.

Maggie told me about the special equipment that she uses at school to help her with her visual impairment. She informed me that she uses a cane. She also uses big-lined paper. Another piece of special equipment used to accommodate Maggie's visual impairment is a CCTV. She explained, "It sits in front of me on the table and it has a tray connected to it, allowing me to set my papers on it. It makes the words bigger, and helps me see what I'm drawing." She also uses magnifiers, but said that they don't make it easy.

As for her social life, Maggie feels that she has a lot of friends at school. She also appreciated the fact that her sister shares her friends with her. In fact, when we looked at pictures of Maggie's recent birthday bowling party, there were a number of smiling children, including her sister's friends at the party. When I inquired if she felt bigger after her birthday, she affirmed and added, "I feel like a total out of control maniac." She then told me that she did some things to put herself in control. She candidly shared, "Sometimes when I'm nervous, I sit in a chair by myself." Later in the conversation, she commented that her mom didn't have any friends at all.

Maggie told me about her "favorite boy in the whole wide world." She said that he is not in her class this year, but he is nice to her. She said, "He just wants me to be his woman." She said they are both eleven years old and they have a special relationship with each other. That's how she knows he wants her to be his woman.

As for her relationship with her sister, Maggie claimed that they didn't spend any time together due to Megan's immaturity. Megan overheard the comment and scoffed as she got a snack from the refrigerator. We laughed at the interaction.

Towards the end of our interview, Maggie's mother, Alice came into the kitchen and listened from a distance. She joined us at the table and we talked about the recent Joubert Syndrome Conference in which Maggie approached the podium and requested to be the president of the foundation. The acting president allowed Maggie to speak to the audience. I had already read the e-mail Alice sent concerning the conference, but was pleased to hear a personal rendition of the stories. The first thing Maggie told me when I inquired about her attendance at the recent conference was, "Actually I got elected as president of the Joubert Syndrome Foundation Conference." She said she had given a speech that was so important that people had to get out napkins to write on them. She thought she said something about eating a high fiber diet.

When I asked about what she did at the Joubert Syndrome Conference, Maggie stated that she got to do "tons of artwork". She shared, "I like drawing. It helps me express the way I feel. I've been practicing for a while." I commented that her sister liked to draw as well. Maggie told me they had a lot of things in common including drawing, and reading books and watching a certain Japanese cartoon.

When asked if she did anything special at the conference, Maggie answered that she got to have two glasses of orange juice. "I like orange juice.

My sister likes no pulp. I like pulp,” she added. This began a conversation about Maggie’s diet. She spoke very knowledgeably about her nutrition. The topic resurfaced several times throughout our discussion, as it had with the other family members as well. “I’m on a high fiber diet. That helps me control my cholesterol,” she explained. Maggie said when she doesn’t like something she has to eat she says, “Yuck. Get this out of my way!” She used expired soymilk as an example. However, she assured me that expired graham crackers are still tasty, especially the chocolate ones. She explained to me how to keep them fresh for a long time.

As I attempted to ask another question, she was somewhat fixated on the graham crackers. We discussed the important topic for a while longer. She added, “I like chocolate because it gives me energy more faster.” This tendency to remain on one topic seemed consistent throughout the interview. I wondered if it was because her mind was full of multiple ideas; yet her delayed speech was preventing the thoughts from getting out quickly enough.

I asked Maggie to tell me about the hospital since she had been there a number of times. She answered that it was on an island and that it wasn’t very dirty. When asked to tell me about how she had been sick, she intelligently answered, “I had bowel resections, and peritoneal dialysis, a kidney transplant and lots of hemodialysis. And in the middle of the hemodialysis, I got allergic to heparin.” She said she felt “yucky”.

I asked Maggie what made her feel happy when she was hospitalized. She mentioned, “the things that made me happy was that there was always

people by my side. And, people giving me presents saying get well soon.” The thing that Maggie states made her feel sad was the bereavement ceremony at the conference.

It was evident that Maggie had positive feelings about the doctors and nurses at the hospital. She couldn’t think of anything she would like them to do differently. In fact, when she grows up, she plans to work there and be a cancer doctor. When asked about her cancer, she informed me, “It’s called post-transplant lympho-proliferative disease. The cells are multiplying that aren’t supposed to be there.” She said they treated it with chemotherapy. The chemo made her feel like she was dreaming. I inquired about her dreams. “I dreamed I was out sitting on a boat and playing cards with my mommy.”

Maggie was proud of her bravery. She believed she got it from one of the surgeons in the hospital. She attributed this doctor with bravery because “she does things without crying or screaming.” Maggie denied crying when she gets painful procedures at the hospital. She claimed that she was always brave, despite my acknowledgement that most kids would probably cry. “I’m much more mature than you thought. I’m much more mature than anybody in the whole foundation,” she assured me. She explained how some of the kids were drooling and dribbling.

When asked about her at-home schedule, she told me that she takes a bath. Sometimes it is difficult to reach her backside when she’s scrubbing, and someone comes to help. Otherwise, she said she does it by herself. Another thing she does at home is take a lot of medicine. She claimed that she was used

to taking the medicine, but remembered there was a big confusion when she first started taking one of the medications. She informed me that she takes a particular medicine that helps her focus on what she is doing. She explained to me how the prednizone helps her in not rejecting her new kidney.

Maggie was very specific about her medications, which ones assist her in certain ways, as well as which ones taste particular ways. One of the medications “makes me a little bit nicer than I should be,” declared Maggie. She said that Tim would mix them for her so that she couldn’t taste the one she doesn’t prefer. When I inquired about the one she didn’t like, she answered, “It tastes like sand.”

Maggie described herself as “a scientist, and a popular kid, and I do stretches and I’m active, and I play ball, and I also do sports like running and jogging and hiking and rock climbing. I’m very active.” When she is sick in the hospital and unable to be active, she dreams that she is playing sports. Her mother believed these claims were a bit inflated.

When I asked Maggie what some of the good things were about her life, I was amazed at her response. She replied, “The good thing is I am starting a new life. I ended my old one a few months ago, and I’m starting a new one.” Her old life consisted of “kidney failure, hemodialysis, and peritoneal dialysis.” Her new life is “a whole lot better.” It includes acting, being active, playing, watching the news, reading the newspaper, magazines and books. According to Maggie, the hard thing about her life is that she has to make sure that her sister doesn’t make

a mess. She also has difficulty in choir. “It’s hard, you have to keep up with the group.”

Alice asked if I had time to look at pictures. She pulled out a photo album already filled with pictures and memorabilia from the summer that was currently coming to a close. We looked through the photos along with both of the girls; they seemed to enjoy telling me about each picture. There were plenty of silly pictures and lots of smiles. There were photos of Maggie proudly approaching the podium of the president of the Joubert Syndrome to ask if she could be president.

In the same trip, an unfortunate accident occurred when Maggie fell down a flight of stairs. Her mother was out alone with the girls, and had to run and get help from the hotel while they waited for her. The photos showed her wrapped ankle; they told me how they had to carry her everywhere after that, since some of the places they went would not accommodate her wheelchair.

Pictures in the album included a yearly get together of the family at the cemetery where her son is buried. The family has a reunion there each year in remembrance of the members that have passed away. Alice admitted that it seems strange to be sitting on the grave markers of her dead family members, and smiling. I recalled a similar feeling when looking at pictures of myself smiling beside my son when he was sedated in a pediatric intensive care unit.

Fred’s Interview

Maggie’s father, Fred, seemed to be a reserved man. Divorced from his wife and mother of his children, he lives alone in a nice suburban home on the

outskirts of Houston. He lives within 15 minutes of his children. The two parents seem to get along well for divorced parents. Both parents report that they do not go by a formal visitation schedule, but rather work with one another on the convenience of when their daughters spend time with each of them.

I interviewed Fred at his home when the girls were with him. Maggie sat at the table on and off throughout the interview. She assured me that she had more history than her father did, and was a much more informative source. It was humorous to watch the interaction between the father and daughter. Fred was reticent to talk to me in the beginning. After the initial awkwardness, he offered a great deal of detail.

For about a year, he reported that there was a large amount of coordination required in taking care of Maggie. Now that she is feeling better, the main issue is simply keeping up with her medications. When she is not in the hospital, managing her medications is a big deal since she is taking ten different medications. The family keeps a medical journal of Maggie's medications so they can keep track of the medications she has taken. That helps keep things straight when going from one parent's house to the other's house.

In reference to adjustments in lifestyle and caring for Maggie, Fred referred to the difficulty of keeping up at work and having to give up work assignments. Fred is an engineer at a government facility. His company has been understanding about his time off to be with his daughter when she has been sick.

Fred went to the hospital at night and on the weekends, and one night per week. That arrangement, alongside work, was difficult. He was either at work, or at the hospital, or driving between the two places, but never at home. He would normally get home after midnight and get up for work at six a.m. when his daughter was hospitalized for extended stays. Maggie went back for a week on several occasions. Later, when she began chemotherapy, he would go back for her chemotherapy for one night about every three weeks. The doctors would also routinely have to perform spinal taps, and MRI's on Maggie.

Maggie had her kidney transplant in March and her father stayed with her for ten days. He took two weeks off work at that time. Three months later, in June, Maggie became ill. In August, she was in PICU for a month. This was a tough time for Fred. The roughest time was the first week. There was extensive at home care in between her hospitalizations. The following January, he took a month off work because he "couldn't take it anymore." The subsequent dialogue tells of the extended hospitalizations and at home treatment.

The family expected just an endoscope to check her ulcers due to the fact that she was passing blood. However, when they performed the test, it was apparent there were perforations. The surgeon's plan was to go in and correct the problems. The problems were much more extensive than anticipated, amounting to a total of about thirty holes with half of them perforated. The two-hour expected surgery ended up taking eight hours. Surgeons had to extract the entire intestine and go over it inch by inch cutting out the tumors and bad tissue. They replaced her intestines and sewed her back up.

Maggie ended up with an extensive month-long stay in the PICU where she developed fluid build-up in her tissues. Fred said they call it third spacing. It was at this time that an oscillator was used to assist Maggie's breathing. Fluid was pushing up into her lungs and collapsing the organs. The oscillator was not enough to keep her going. Her surgery was on a Thursday. On Monday, she had another surgery to reopen her and reexamine her condition. They drained fluid at this time as well.

The surgeons decided to leave her belly open so that they could come in once a day and suction that area. Maggie had plastic covering her intestines, but there was room for the doctors to have access as needed. "It was pretty nasty," according to her dad. "I didn't think she was going to make it. We had the priest giving her last rights, and everything." She spent two weeks on the oscillator for breathing assistance.

Fred gave extensive details about Maggie's care and condition that painted a vivid picture of its serious and stressful implications. She had drains from having her intestinal surgery. She also had a g-tube in order to drain her stomach. She had another tube for feeding. This tube was difficult to deal with because it leaked, and was a mess. She was hooked up to a pump for continuous feeds as well as an IV to get the correct amount of fluids. She liked to eat chicken broth and drink during this time. However, it was just for pleasure. Everything would come immediately out of the G-tube. Her parents had to measure all output from the g-tube and continuously replace the bag.

These tubes were in place from August through January. In January, she had her surgery to reconnect her intestines. Maggie interjected from the other room, "I'm reconnected, but I still like liquidy stuff." After that time, Maggie was able to eat solid food within a week. She still had the g-tube for almost a month after the surgery. According to her dad, "that was the stuff that was hard to deal with."

The whole time she was in ICU that month, the family stayed in the waiting room designated for the pediatric intensive care unit families. Fred said he went to work for part of the day, and then he would relieve Alice so she could take a break. He stayed most of the weekends.

He added that Alice played music for Maggie and rubbed lotion on her arms and legs to keep the blood circulating and get the fluids out of her tissues so that she wouldn't be so swollen. They were very involved in her care, and helped the nurse give her a bath. Dad disclosed, "That was real hard, especially when her stomach was open."

Maggie interrupted the interview and wanted to color. She said we were in her favorite spot where there was the most light. Her dad suggested she take a bubble bath, but that idea was met with an adamant "NO!" Even the idea of filling it up with suds and pretending she was in a cloud did not lessen her insistence that she did not need a bath. Maggie also mentioned numerous times that she wanted triscuits to eat. She finally settled for a cucumber and sat at the table and ate the entire cucumber. She told me that I am very weird because I only like cooked vegetables and not raw ones. I confirmed that I often get made fun of

about my eating habits. Sponge Bob was on the TV in the background throughout our interview.

As I talked to her father, Maggie “assisted” and added details to his story, often talking over him, and spelling such things for me as “We call it PTLD, post transplant lympho-proliferative disease l-y-m-p-h.” She is countered with her father’s frustrated response, “Maggie!” Her dad explained to her that PTLD is a terrible case of mono, but that it’s so bad that it’s like cancer, and makes tumors. He patiently answered her question “What are tumors?” “They are little growths that aren’t supposed to be there.” He informed her that she had a couple on her liver, and a couple on her lungs, and a whole bunch throughout her intestines and her stomach. She added that her swollen lymph nodes made it hard to cough. Maggie’s speech is high-pitched and slow and deliberate. Her headstrong personality is actually a joy to hear. She continued to explain that now it is easy to cough since she doesn’t have swollen lymph nodes anymore.

Fred said he tries not to think about it, but when he thinks back on it, it’s hard to focus on. There was no time for outlets such as working out or stress relief. He says, “I didn’t have much of a life.”

DORSETT FAMILY

“Homes from the \$170’s” was advertised on the sign at the corner of the street I turned down, as I followed the directions to the Dorsett’s home. The suburban neighborhood was clearly a new subdivision, as construction was still underway along the streets. I took several turns to find the corner 2-story home with the manicured yard and typical rock-lined flowerbeds leading to the front

door. I was welcomed by April's mom, Valerie, at the front door. Valerie is a light-hearted black lady. She led me to the living room where her two daughters were watching an African American sit-com on the big screen TV.

The girls were very receptive throughout my explanation of the research and my goal, which is to help other people going through similar situations with a sick child in their family. Their father, Aaron, was not able to attend the introductory meeting, due to his unpredictable work schedule. He did, however, agree to meet with me for an individual interview on another occasion.

As I observed the house around me, I was impressed by its cleanliness and tasteful design. Valerie offered me a seat wherever I was comfortable in the living room. The two sisters were propped at opposite ends of the overstuffed taupe-colored couch. Both girls were buried in the throw pillows as we talked of their experiences with April's illness.

April is an 11-year-old girl suffering from Lupus. She was diagnosed less than one year ago and has experienced a number of hospitalizations and medications due to her newfound illness. The discovery began one morning when April awoke with the left side of her face and her lips twitching. "My face was just twitching and we didn't know what it was," April recalled. She rushed to tell her mother something was wrong. Her older sister, Alicia, who is now 16, recalled that April could not speak clearly that morning. Valerie, could not imagine what was wrong. "I had blood clots coming from my mouth and nose for a couple of days." April also had some spots on her body. "My moma and my daddy thought it was chicken pox."

With the additional symptoms of her daughter on this morning, Valerie knew something just wasn't right. There were just too many unusual changes in her condition. Valerie took her youngest daughter to the emergency room twenty minutes away. April relived the event as she told me that she walked into the hospital from the parking lot and then everybody "rushed and rushed. You know how they put you on the bed and run. Well, that's what they did," she stated.

As we reviewed April's hospitalization, she ran into the other room and came forth with a large framed photo of herself surrounded by doctors. Valerie explained to me that April was chosen to be in the photo and that it hung in the hospital hallway along with pictures of other children in the hospital. The family is obviously proud of the photograph and the fact that April was chosen to be the subject of the illustration. Her mother believed that April's being chosen for the photograph was confirmation that God was involved in her daughter's care.

April shared her recollection of her original hospital stay with me. "I just remember they did a whole lot of stuff. That's all I know." According to her mother, she was heavily sedated and medicated for most of the month she was in the hospital. April knew that she was placed in ICU; however, she had no memories of that time period. The doctors reported that her brain damage affects her memory. April recollects some events, but has no memory of others. April's heavy sedation continued as she began her recovery in a regular hospital room. However, she recalled her family's frequent visits despite the sedatives.

While residing in the regular room, sometimes April was permitted to go to the playroom. She preferred to do artwork when she visited the playroom. She distinctly remembered, "I had to carry this little machine around. It had water or whatever in it. I couldn't go nowhere without it." When reminiscing about her time in the art room, April contributed, "I seen a lot of kids that were different, with different illnesses." Seeing children with so many other illnesses made April sad. "But, then, sometimes I felt better because I felt like I wasn't the only one who had sicknesses."

In her own hospital room, April also spent time coloring, drawing and thinking. She attempted to distract herself by focusing on topics other than her physical condition. She envisioned her friends and how she previously spent her time in school. "It kinda helped me soothe my mind. I wouldn't be like, what's gonna' happen next?"

April was not always at ease with having all the poking and prodding of the needles in the hospital. She claimed that now she is used to it; it doesn't bother her since she has become accustomed to the procedure. "It really don't hurt no more now that I'm used to it," April confirmed. She prefers to watch as she gets a needle stick. However, she explained that they don't allow her to watch in order to prevent her from moving at the time of the stick. "My momma just turns my head."

April is presently undergoing chemotherapy once a month. She depicted a current hospital stay for a chemo visit. She goes to her hospital room, puts on her nightgown, gets comfortable and gets in the bed. Then the medical routine

begins. The staff comes to weigh her, and take her blood pressure on a regular basis. Next, they “give me the shot or whatever, and take the blood.”

She thinks blood work was the process utilized to diagnose her Lupus. April explained how her blood cells were fighting each other. She was uncertain which cells attack which cells. She proceeded, “Then they poke me. That’s when they get the IV.” She concluded that sometimes she becomes nauseous towards the end of the treatment. On occasion, she vomits; other times, she just feels sick at her stomach. The treatment continues for a day and a half, according to April.

When I asked about her knowledge of her treatment, April disclosed, “I really don’t know what it helps. I just know it takes my hair out.” We discussed how her hair fell out in clumps. April’s hair loss was an upsetting side effect for her. Her sister was disturbed at the sight of the hair loss originally as well. She shared with me that her daddy shaved her head with an electric razor when she originally lost her shoulder-length hair last year.

April had a big adjustment this year with school. She moved; therefore, she had to make all new friends and adjust to the grade change as well as her physical differences. April’s mom wrote a letter to her teachers explaining her medical condition and apprising them of the fact that April had brain damage due to her stroke and illness.

One teacher in particular seemed unreasonable in her accommodations for the special needs of this student. Valerie shared the teacher’s letter in response to the letter she had written on behalf of her daughter. I include the contents of this letter as an example of the obstacles that this family is beginning

to face with regard to their simple requests for the best in their daughter's education.

The teacher replies:

Mrs. Dorsett,

Thank you for the note. I have taught school for 22 years and have seen my share of students. I have tried to give April the added attention because of her health problems and her home schooling. Getting in the groove has been hard for several of the students, not just April.

I told the students to write the words down first before they look them up because I would turn off the overhead. The words are always on the bulletin board.

I can't comment on not answering her, not sure when this occurred.

She is struggling through. Her grade is a 68 for the first three-week period. Of course she just got two more papers back and those aren't in the grade book. She can redo any papers for a 70. I hope this has helped.

I was dismayed at the fact that this teacher was so mechanical in her response to the special needs of this student. A small accommodation was all that was requested in this particular incident, as I perceive it. I spoke with April's mom about the reply. She was frustrated at this response; she planned to go to the open house and talk to that teacher in person. Valerie was not aware that

April was eligible for special accommodations due to the girl's disabilities. Valerie is planning to inquire about special needs considerations for her daughter. She will request a letter from the doctor so that the teachers will better understand and comply with April's needs.

April's Interview

April preferred the homebound school and is convinced that she learned more from the teacher coming to her house than she did in the traditional classroom. The teacher could assist her as needed; otherwise, she could proceed with her work at her own pace. It was interesting to note that the homebound teacher came only four days a week for one hour; the child still felt she learned more through this process. Her mom said she enjoyed the one on one attention of the homebound teacher. She was taught homebound from September when she was in the hospital until this August when returned to the regular classroom.

April referred to some difficulties in the classroom. She finds it difficult to concentrate while the other kids are so noisy. She does not recall the noise level ever bothering her prior to her stroke. She hypothesized the reason is that she was previously used to the high noise level. Her recommendation for the teachers is to "just keep their class quiet."

April also believes that she is unable to understand the newly introduced concepts at the same rate as the other pupils. She perceives a lack of assistance from the teachers. She referred to the teacher not leaving the words on the overhead projector long enough for her to copy them down on her own

paper. The teacher asserted that the words were always on a bulletin board and she could copy them any time on her own time. The problem with that arrangement is that April is not permitted to get out of her seat when she attempts to copy them off the board.

April's limitations are minimal in relation to her daily tasks. She is required to stay out of the sun. She finds this to be inconvenient when she is trying to live a "regular life". She does like the fact that when everyone else is required to run and sweat outside, she does not have to participate.

As for negative things about her life, April commented, "I have Lupus and eczema. I can't do a lot of stuff in the sun. If I have open sores, I can't swim because it burns." She is required to apply cream when she gets out of the shower or her skin becomes excessively dry. April alternates her numerous medications. One day she takes eight pills; the next day she takes nine pills; every night she must take an additional three pills.

When I inquired about April's response to disturbing situations, she replied, "I itch." In fact, April's eczema had been mentioned several times throughout our interviews. She suffers from extreme eczema, or dryness, of the skin. Her mother is convinced that April's Lupus was caused by a reaction to medications used when April was a participant in steroid studies. The skin condition almost appeared more bothersome than some of her other health issues. April explained that the eczema is related to her Lupus in the sense that she itches when she has to take her pills or perform some other task that makes her uncomfortable.

When I asked April what helped her through hardships in her family, she responded, “We really don’t have hard times.” I question her if it’s hard when she is in the hospital. “Yes,” she affirmed, but she is getting used to it. April’s advice to other families undergoing a child suffering from an illness is to “stay strong and believe in God”. She added, “Do what you can to stay up.”

As for advice to the doctors, April recommended, “I really don’t know what they did.” She was under the effects of medications most of the time. She mentioned that she likes it when the nurses and doctors are happy. She wanted them to “try to help me instead of just poking and poking until they can get it.” To help her, they could tell jokes or make her laugh.

April and I conversed for quite some time when she had to excuse herself to go to the bathroom. She held up one finger as a gesture, but could not speak. After a minute, she returned and apologized; she said she had to throw up just a little. I assured her we could finish another time when she felt better. However, she opted to continue the interview. Only minutes later, the same episode occurred. As she opened the hallway bathroom door, adjoining the formal dining area where we were talking, I could see her crouched over the toilet. She was obviously throwing up. My heart felt sad for this young girl with such a positive attitude. She apologized when I went to check on her. She conceded that we should finish the interview later.

I commented that I hated to see her sick like that. Her father replied that they all hated to see her sick, but that they have had to get used to it. When I

inquired if they could give her medication for the nausea, he told me she is on so many medicines that “they don’t want this one to counteract that one.”

April finished vomiting and came into the den while I was looking for my keys. She offered to help me find them; she then proceeded to give me the bead bracelet that she made me with my name on it. April seemed proud of her skill of making bead bracelets. She sells them for three dollars each; mine was perfect, made with bright colors just as I requested. She appeared elated; I was equally thankful and happy to wear it.

Valerie’s Interview

Valerie, April’s mother, is a heavy-set black woman. She began exercising in the last six months and considers this time her “me time. No cell phone, no ‘mama this’, just me for a couple of hours.” She includes the exercise regime in her day about four days a week. She goes in the morning so that it doesn’t interfere with her schedule.

Valerie considers herself patient and open-minded. She does not worry about tomorrow. She realizes “you plan today. It could be totally different than what you think.” She hopes to have the mind of Christ and recognizes that you can’t expect people to think a certain way because all people are made differently.

Valerie believed that the worst thing in the beginning of April’s sickness was “just not knowing. Once you know, you can deal with it a little better.” In order to cope, Valerie reads her Bible. She believes it is the instruction book for life. She feels that April has always been positive. She instructs her children to

“focus on God and let him lead and guide.” She said we couldn’t question why, but rather focus on God. “He gave me strength even when I was running out of gas.”

Valerie acknowledged that she would not have been able to undergo the stressful events without her “prayer partners” from her church. These friends were there for her in times of need. Practically speaking, they prayed for her, called, and brought food to the family when April was hospitalized for more than a month. On one occasion, her friends stayed at the hospital so that she could go to church. The only other time that Valerie would leave was to go take a shower. She admitted, “Sometimes you just need to get away.” She is thankful that she had family and friends to support her.

Valerie claimed, “even if we thought death, we never said it.” She stated the reason for this was that their beliefs were to have faith and speak with authority. Valerie said her friends comment that she never prepared them for what to expect when they went in to visit April in the ICU. Even if someone thought death, she did not want to hear it at that point. She also objected to anyone praying for God’s will. There was a time when a chaplain had come to pray for April when she was very ill. The chaplain had prayed that God’s will would be done. Valerie stated to me that the prayer contradicted their belief that you should claim your prayer and believe it will happen.

Valerie did not feel that she could have made it without her family and friends. “Sometimes people just want people there.” She believed that she would have been receptive to other people’s help if she had not had family support. It

was comforting to know that there were family members who were going to visit each day, even if it was for just five minutes. "It's tiring for them to change their lifestyles too, but they did it." This break allowed her to have some time to spend with her other daughter. Valerie thought about her other child being neglected, but she realized what was most important. She tried to prioritize and achieve balance during this demanding time period.

It was fortunate that the family had decided to get health insurance one month prior to April's illness being diagnosed. No one in the family had ever been sick. During the grace period of the insurance, April began getting sick and was diagnosed with Lupus. The sole reason the insurance covered the illness was that the family was able to prove the illness was not pre-existing.

Even with the insurance, Valerie is sure that they will never be able to pay the full hospital bills. Her friend who works in medical records estimated that the hospital bills were close to \$250,000. They had recently filed bankruptcy prior to April's diagnosis. "You can't worry about everything. You just go on. You have to give it to the Lord," believed Valerie. "I still have to buy her medications for her to live. I still have to feed her."

April's parents have been married for seventeen years. Valerie discovered during her daughter's illness that her husband did not handle the pressure well. She felt that she had to handle everything and make all of the decisions. This burden was difficult and made her feel all alone and frustrated with her husband for his lack of support. That was a side of her husband that she had never seen before.

She relayed the story of taking her daughter to the emergency room on the morning she woke up with her face unable to move and her speech slurred. Her husband did not go with them to the emergency room. Even after calling her husband to let him know his daughter was in the ICU, he still did not come to the hospital. Valerie shared that one of her friends called him when he was not at the hospital. Following that call, he was there for her. She felt that he must have needed a “push”. It was several days later that he began to participate in his daughter’s hospitalization.

Valerie does not doubt his love for his daughter, but was surprised at his inability to deal with the situation. Valerie believes that people think women are so strong, but that really they need men to lean on. She still does not know her husband’s reason for not going. She considers the idea that it may have been fear on his part, but an unwillingness to admit it. She said she doesn’t sit and think about it. Once again, her advice is to go on.

Valerie observed an instance when her husband Aaron broke down, upset because April was questioning, “What did I do?” Valerie said that the dad just had a difficult time not being able to help April and see her questioning what she did to deserve this illness.

Valerie stated the reality that dealing with a child with a chronic illness is very time consuming. She doubts she could hold a regular job due to the time demands with her daughter. She needs to be available at any time. Valerie is able to schedule her appointments at her salon around her daughter’s hospital schedule. April dreads the hospital visits; currently they stay in the facility for

twenty-four hours. In addition to chemo, April has also received dialysis treatment in the past.

As a mom, Valerie had trouble even explaining how she felt. She thinks that now she could tell someone that it is not as bad as it looks. However, she recalled the time when she was not knowledgeable of the different treatments. She said at that time her feelings were, “What’s going on? Is she going to die?” She believed that nurses see these types of situations everyday; they don’t panic.

She remembered one time when April was very sick; she received conflicting advice from friends and family about moving her to another hospital. Valerie did not feel that April was well enough to transfer to another hospital. She commented that she had to put all her trust in that doctor, that she would help her daughter recover.

Valerie described several instances in the hospital. The medications April was taking caused her not to act like herself at all. Her hands moved erratically; the family and doctors were unable to determine why. On one occasion, her mother witnessed April suffering from a seizure.

Alicia’s Interview

My next visit to the Dorsett’s house was to interview April’s sixteen-year-old sister, Alicia. She and her mother were running late from a hair appointment at her mother’s beauty shop. It was nine p.m. before they were able to meet with me. Thursdays and Fridays are “late days” sometimes according to April and her

father, as we waited on the rest of the family. When the girls arrived, the family ate fried chicken served informally from the kitchen bar.

Alicia appeared older than sixteen as she came in the back kitchen door with her mother. She was dressed in black, her hair all fixed, and wearing more make-up than I remembered from our previous encounter. She later enlightened me that her beautiful gray eyes are colored contacts.

Alicia laughed and responded, "I don't know!" when asked to describe herself. She said that she likes to go out and hang out with her friends, go shopping, and go to the mall and look at all the boys. She considers herself a prissy type, "I gotta' be cute all the time." Alicia thinks of herself as a very emotional person. She believes she can be emotional and strong at the same time.

As for a schedule at home now, Alicia does not think that her family's routine has changed since April was diagnosed with Lupus. Alicia will continue to go to school in her previous school district even though her family moved last year. Her grandparents still live in the near-by town so she can maintain an address in that district. She is glad to stay there in order that she can complete cosmetology school and maintain her current friendships. Alicia did not think there were any additional responsibilities that had been added to her list since her younger sister's hospitalization. She said that nothing had changed. Her sister had always requested her assistance on everything. The girls laughed over this exchange.

For the months when April was in the hospital, Alicia's daily life was greatly affected along with the rest of her family. Alicia stayed with her father's parents in a near-by town and was able to continue to attend school. Almost every day, her grandparents drove her the 30-minute trip to the hospital to visit her sister. She would go to their house after school and do her homework; after everybody got off work, they would head down to the hospital.

When asked what she did at the hospital, Alicia responded, "Really, I would just sit with her. I cried every time I went though." She went on to explain that when April was in the ICU, she cried every visit. Once April was transferred to a regular room, she only cried sometimes. She concluded that she "had to deal with it."

When asked what was upsetting about the experience, Alicia replied, "It was hard for me to see her like she was. She was hooked up to all the machines, and I didn't know what was going on. I hadn't ever seen anything like that before." I asked Alicia if it would have helped if someone had explained the purpose of the equipment to her; some hospitals' child life specialists help children understand the equipment when a family member is in the ICU. Alicia seemed uncertain as to whether or not this would have helped her deal with the situation. She still feels that when she would see her sister in that condition, she would respond in a similar fashion, crying each time. "You can tell me, but I'm probably going to have the same response."

When Alicia recalled her sister's stay in the ICU, she said that she would visit several times a day. She said that she would go in and see April after she

finished calming down and crying. She shared, “I’m not thinking she’s going to be like that. Why’s she got that here? Why’s she got that there? Why is she all hooked up like that?” Alicia elaborated that she had never lost anybody close to her, nor had anyone close to her ever been sick. She wasn’t prepared for what she experienced with April’s illness.

Alicia detailed the visits and time at the hospital. Her sister was often greatly medicated and did not even recognize her a lot of the times she visited. Looking back, it didn’t feel like her sister was in the ICU for too long; however, the stay in the regular hospital room seemed like forever to Alicia. She never stayed at the hospital overnight with April. There were a few times she remembers going with her daddy and staying until 2 am. Her mom was there every night.

The most difficult thing for Alicia during that time was the thought that April might die. Her mother had mentioned that the family never discussed this possibility out loud. When I asked Alicia, she confirmed this fact. I asked her why she never talked about her fear. Her reply was, “Because, we didn’t want to think like that.” She admitted that she did think about it in her mind, but didn’t mention it aloud. She dealt with the thought by thanking God and keeping hope that nothing bad was going to happen.

As we were discussing this sensitive topic, April popped in the room, bubbling with curiosity as to what we were talking about. April immediately wanted to participate in the interview; however, her sister reminded her that she had previously been interviewed and this was her turn to talk. Alicia exclaimed, “I

thought this was my interview. What you doin' in here?" The girls' sibling quipping was cute.

Alicia gave me additional insight into how the family deals with difficult situations. She told me that they had family meetings. In the meetings, everybody would try to say what was on their mind. Alicia relayed the meetings are usually called, "Ya'll just come downstairs with your Bibles." The members then discuss the reason for the meeting at hand. Alicia says, "Me, I never make it. I cry every time, because I have issues of my own. That's the way I deal with things. I don't talk about stuff too much." Alicia adds that when April was in the hospital, there weren't really family meetings during that time. "Everybody was just running here, and running there," she recalled.

Alicia continued to explain that she was in school for the duration of April's hospitalization. She does not recall any absences. She was able to carry on her schoolwork successfully. While in class, she would convince herself everything with April was ok. She admitted it was a different story when she would go visit and see her sister, with all the tubes, and hooked up to all the machines.

Alicia's friends were supportive and often asked about her sister's condition. The peers would try to help in whatever way they could. She feels that friends offer support during difficult times by helping the person think positively. She appreciated their efforts to distract her and keep her mind off of the worse case scenario.

As a sibling, Alicia never recalled feeling left out or neglected. She was aware of how sick her sister was, and did not begrudge her the time away that

her parents needed to spend with April. She said that we all have our times.

Alicia added that even though April was hallucinating, she would still call out for her mom. She knew that her sister needed her parents at that time.

Alicia remembered feeling happy when, after one of her visits, her sister asked why she had left. Often times, April was highly medicated and unaware of what was going on around her. "Most of the time, she was out of it. There was only a couple of times when I went that she was really herself and we had fun like old times, where we laughed and stayed up late at night. You know, being sisters. We had a couple of those times."

According to Alicia, the two sisters have a balanced relationship. They get along mostly, and fight sometimes. April's sickness has not affected their relationship. Alicia doesn't think her sister has changed. She says, "She still has the same attitude she has always had." Alicia said that April sometimes asks a lot of questions and becomes irritating quickly. Alicia feels that others can help by just being patient with April when they are dealing with her; sometimes it is hard for her to remember to be patient with her sister. She whispered that she is "just like her daddy".

As for the hospital staff, Alicia thinks that some of the nurses interacted well with her sister. She acknowledged that April had her favorite nurses. Overall, she feels that the nurses should have watched her more closely. She cites a time when April fell out of her bed in ICU, despite the rails on the bed being raised. Alicia stated, "She didn't want to be like she was. She was being fed through a tube. She was very strong. They had to restrain her. She was

scooting down and fell out of the bed.” Alicia feels that her parents should have been allowed in the ICU unit at all times. Her mother was asked to leave the unit and was not able to watch April. Alicia is convinced that her mother’s absence is the reason her sister fell out of the bed while in the ICU.

After the interview with Alicia, April and her mother were on the living room floor looking through pictures to show me due to the earlier discussion that we had about April’s “braid wig”. She advised me, “My moma had made a braid wig. I wore it. It looked like I had half hair. It was in a do-rag with the cornrow braids glued on top of it. I could take it off and put it back on.” The braids were past her shoulders. Both sisters seemed disturbed about the initial shock of April’s hair falling out by the handful. The family candidly talked about their feelings of her losing her hair and showed me pictures of Aaron shaving his daughters remaining hair after the chemotherapy treatment. There was also talk of April celebrating her birthday in the hospital. Pictures depicted a number of family and friends gathered in the hospital playroom for her birthday celebration. This year she was able to have some friends over for a sleep over at home when she turned twelve.

Aaron’s Interview

The large framed picture of April with the doctors was still propped by the doorway weeks later when I interviewed April’s father, Aaron. Aaron was dressed in casual clothes and commented that he forgot I was coming; he was about to cut the grass. He happily retreated to the formal dining area where we talked about his family’s experience with his daughter’s diagnosis of Lupus.

Aaron is a stout black man with a funny sense of humor. Throughout my different interviews and observations with the family, it is clear that he teases a lot and has a positive attitude. Once he told me I would have to mop floors in order to observe his family. When I asked his age, he lied to me and answered twenty-five to see how I would react. In reality, he is thirty-six years old. It was touching to see such a big tough man talk about his helplessness and uncertainty in dealing with his daughter's "terminal illness", as he referred to it on several occasions.

Aaron is a fluid tech, checking fluids on oilrigs. He works twenty-four hours a day, twenty-one days on work, seven days off work. He carries a cell phone and is on call if needed. Sometimes he is gone for several days; other times he goes to a job and returns home nightly.

Aaron described the Monday morning that April woke up and couldn't talk and feel the side of her face. They took her on to the emergency room. He did not mention the fact that he initially remained at home. It was at this time that she was put in the hospital. He thinks she was in the hospital for two weeks. He was working at the time, but he remembers being at the hospital and leaving to go to his jobs.

Aaron was appreciative of his job and the way his company handled his family's crisis. He described his company as big, but small. He didn't have to go through sick leave. He explained, "They know your child is in the hospital. If their child was in the hospital, they know they would want to be there," so his bosses would tell him to stay there with his child.

I asked Aaron about the financial stress of the hospitalization. His wife had mentioned their bankruptcy. Aaron did not comment about the bankruptcy, but did give the following insight. “You just do what you can do, and don’t even worry about it.” He talked for a while about how much money the doctors make. He recognized that the doctors did go through a lot to make large salaries. But, he is realistic and claimed, “Everybody can’t afford to pay that kind of money. What are you going to do? Stop living just to pay them so they can live good. You’ve got insurance, so you let the insurance pay, and then you pay what you can. Don’t stop your life.”

Aaron stated that the hospital bill for the month that April was in the hospital was \$150,000. We looked through the bills, and in fact, his wife had given me a copy of that bill, reflecting the PICU bill at \$2,600 per day; the private hospital room was \$700 per day. He stated that this was simply the hospital bills. There were also all of the individual doctors’ bills that come separately. We agreed that very few people could actually afford to pay these steep prices. Aaron believes that if you talk to the right people, you can get financial assistance. They had gone to several people who said that they made too much money for financial assistance. Then, a friend of the family helped them get financial assistance.

The biggest complaint that Aaron vocalized about the hospitalization was that the parents were not allowed in the room at all times with their child. For confidentiality reasons, the hospitals request that families leave when they are exchanging information regarding other patients. Aaron responded, “What they

don't understand is parents don't care about what's going on with the child beside them. They want to know what's going on with their child."

He is frustrated that the parents are not allowed to be in the unit while the doctors are there, and then the doctors leave without informing the parents of anything. Aaron feels that April fell out of the ICU bed because the nurses took too long when they were changing shift and were not watching his daughter. He does recognize that during a shift change or if another child is getting a procedure performed, the parents would have to leave. However, he feels that when the doctors are making their rounds, it is the precise time when a parent needs to be present to address their concerns.

Aaron acknowledged that his daughter has some excellent doctors. He cited an example of one doctor staying up all night long trying to figure out what was wrong with April. There was a team of doctors treating April. Her father laughed as he attempted to name the different types of doctors treating his daughter. He struggled to remember some of the different specialists including: "a dermatologist, a doctor for her paralysis, a respiratory doctor, a kidney doctor, a speech doctor, a brain doctor, and a neurologist." He appreciated those who seemed to really care and took the time to inform the parents of their findings. Her case was so complex; the doctors would have special meetings just for studying her case.

If it wasn't for an older doctor, Aaron is convinced that April would never have been correctly diagnosed with the Lupus. Her parents had taken her to all the different local clinics to try and determine what was wrong with her. This

doctor was working late, and immediately recognized her symptoms of Lupus. He explained to me that you have to have a combination of four symptoms out of eleven to be considered a Lupus patient. April suffered from five symptoms, including: the butterfly rash on her face, black dots on her skin, and protein in her urine. The doctor explained to the parents that one doctor could see ten patients a day for ten years, and still never see this in a child that young. Lupus tends to affect people between the ages of eighteen and thirty. Her dad told me that everybody has the potential of getting Lupus; different things can trigger it. Aaron is certain that the Lupus was caused from the steroid treatments that were an effort to cure her extensive case of eczema. He referred to it as Lupus nephritis.

As for knowledge about the illness, Aaron said that you have to learn as much as you can and attempt to understand what's going on with your child. Aaron believes now that in trying to cure one illness, they caused another. Once April was diagnosed with Lupus, friends of the family would bring information for her parents while they were at the hospital. Aaron recommended, "Before you get to panicking and all of that, learn what it is, and see what you've got to do. It's going to hurt. It's going to make you feel sad. But..."

The initial feeling of her diagnosis was concern over whether or not she would live. Aaron acted out a rendition of the doctor giving them the diagnosis of his daughter's Lupus. He illustrated the extreme suspense the family experienced while trying to understand what the doctor was explaining. He laughed now as he reenacted the event. "It was like watching the stories. When the doctor would get to the good part he would pause and break for a

commercial,” Aaron remembered. He recalled the first time she was admitted to the hospital when she was taken in for the butterfly rash. He and his wife were questioning, “What’s going on? What’s going on?” The doctor sat them down to tell them he had bad news. Aaron was able to laugh in retrospect at a very difficult time. He used his voice intonation, pauses in speech, and bodily gestures to portray the painstakingly long discussion of his daughter’s diagnosis. The parents were totally unfamiliar with the diagnosis, and therefore hanging on every word of the physician as he broke the bad news to the parents. He says that his heart was just pounding, as the doctor would lean back in his chair and take his glasses off. Aaron said he and his wife were scared and holding hands and looking at each other thinking, come on, come on, tell us more. He then told me how the doctor went to the chalkboard and gave them a whole lecture on blood. After the lecture on blood, he gave them a lecture on the kidneys since she had kidney malfunction. Next, the doctor wrote LUPUS and WOLF on the board. Aaron told me that wolf is the meaning of lupus, because it is the body attacking itself. The natural defenses are attacking the healthy parts of the body. Aaron said that it was a relief in some ways to get the diagnosis, because they had been praying for answers.

In the discussion with the doctor, the parents had to ask what it was the doctor was telling them. They wanted to know if their daughter was going to survive. Once again, the doctor went into his long oration, and answered stating that many people live with Lupus. Extensive treatment would be required. Aaron paused as he recalled how they dealt with the news. He told me that they didn’t

know what to do. “Basically, they told us she wasn’t going to be the same person. They gave us a real bad report at first. They scared us,” recalled Aaron. “We just took a deep breath. Then we called our mom and let everybody know that we were in the hospital.”

Aaron chuckled when he recalled staying in the PICU overnight room. He believes that they need a room with beds for parents, somewhat like a dorm. He suggested a waiting room and separate room with bunks where people could go to sleep. He compared the overnight room to a Dr’s office waiting room. He elaborated, “Just imagine, waiting in a Dr.’s office. You are sitting in a chair with magazines. How comfortable is that?” The recliner chairs were hard and uncomfortable. They stayed in this room for several weeks. There was one shower. He estimated there were ten more parents there with children who were in the intensive care unit. Some parents were hoping to sleep, while others were crying, others were trying to pray, and still others were wanting to watch TV.

Aaron openly shared, “It’s hard seeing your child laying there, helpless, and there is nothing you can do”. He commented that he still feels emotional about it at this time. It was the hardest time in his entire life. “You can’t help them. There is nothing you can do.” Aaron explained that his family “Drew upon the Lord” to help them through the stressful times. He feels “The Lord has the last say so. You’ve got to stand strong and believe.” That is the summation of his advice to other families experiencing similar circumstances. “If you break down, how can you be strong for your child? You can’t give up and lose faith.” He did not want his child to see him giving up.

According to this father, even though the situation looks bad, it has an end to it. He believes you have to pray everyday and stay focused. He shared how he and his wife would pick each other up when they got weak. I reflected on my other families, and on how many people do not have a spouse to lean on in these times. Perhaps another support person could be equally helpful.

Aaron referred to the family meetings his daughters mentioned as daily devotionals. The family tries to have these get-togethers periodically. Dad added that sometimes when the girls get out of line, the parents try to find scriptures to get them back in line. We laughed about it. “The Big Family Meeting” when the whole family gets together is called “What I Don’t Like About You”. The extended family uses this opportunity to tell what bothers them about the other members without everyone getting offended. They do this at family events like Christmas and Thanksgiving. I had never heard of such a get together. We laughed about it and Aaron assured me that everyone comes away without being too upset.

Aaron’s mom is retired and his parents have served as a big support for the family throughout this time. His mom will go to the hospital if he and his wife have conflicts with work and are unable to be there. However, Valerie’s schedule is very flexible since she has her own beauty salon.

When asked about April’s medications, her father chuckled and went into the kitchen and returned with a medicine bag. He said she takes at least 10 medications. She has a morning plastic pillbox with the days of the week. She also has an evening plastic pillbox. She takes her medications on her own and

refills the pills as needed. Her dad said that she even tells her parents the milligrams; her parents have to find the paperwork for the same information.

He shuffled through the various medicines thinking aloud which medicine served which purpose. Some of the medications were given just to cure the effects of the other drugs. Aaron said that all of the information regarding the prescriptions were in the “binder” that the family takes to each of her appointments. The book contains numerous materials concerning Lupus, bills, letters from doctors, etc.

As for April's education, since she started a new school this year, he feels that the teachers are not sensitive to her illness. He explained how he talked to the nurse to see how educated she was about Lupus. The nurse had attended a seminar, but never been around anyone with the disease. Aaron requested that she talk to her teachers to educate them about Lupus.

He gave an example of the teachers' lack of cooperation with his daughter's needs. April is on fluid pills, but the teachers will not allow her to go to the restroom as needed. He also told how he informed the gym teacher that April can't be in the sun; it can give her serious health problems. The coach still required her to stand out in the sun. Aaron said that if it weren't for his wife holding him back from going, he would have been more confrontational with the schoolteachers. “If she's sick, and that's gonna' kill her. What are you trying to do, kill her? Use your head! If that was your child and she was sick, would you do that to her?”

He uses the nurse to relay messages to the teachers so that the teachers will adhere to the necessary medical attention. He feels that the teachers are beginning to understand. I appreciate Aaron's practical and empathetic attitude in his expectations of other people. I agree with his sentiments. If these people truly put themselves in the position of this child and her family, would they not handle the situation with more care? I believe they would. Aaron said that he was an easy type of guy, but once he gets mad, he's "real mad". He thinks his wife tries to keep him back away from the teachers.

Aaron commented that the kids were being cruel to April. He believes it is because they don't understand why she looks different. The children talk about her skin that is affected by eczema over 99%. Her peers make uncaring comments and request that she not touch them or the ball at recess. Aaron said that April responded by saying, "They don't know." She will walk away when such behaviors persist. He believes that she has gotten extremely strong; her parents encourage this quality. He and Valerie encourage her, explaining that the other children just don't understand her illness.

The parents considered home schooling April, but they felt that she was going to have to learn to deal with such harsh realities in life. He assured me that if the situation gets too bad, they will remove her from it. She does have some friends at school. Aaron described the children that were sitting with her at the table when he recently visited her for lunch.

JONES FAMILY

I carefully followed the instructions to the Jones family residence for the first visit. It was a several hour drive to reach Beaumont, Texas. I turned down Martin Luther King Street as I approached my destination. The house was situated in a dark area of town. As I drove up to the corner lot, I wondered where to park. Later, Casandra told me it was good that I parked on that side of the house. She reassured me that it was better lit, and that would deter crime. The family has lived in this location for several years. I listened as the neighbor came out and shot a gun. "I got a good neighbor. He looks after me," assured Casandra. Somehow, this thought did not comfort me as much as it did the single mother.

The modest older house was the home to Casandra, single mom of thirteen- year-old, Christopher, and his older sister, fifteen-year-old, Cassidy. Casandra, the 35-year-old, casually dressed African American mother was a gracious host as she welcomed me to the mix-matched living area. Assorted pieces of furniture were placed comfortably around the room. The wooden floors of the house were in keeping with the wood frame. For our first visit, we sat in the living area. The children were on one end of the couch. I sat beside Christopher, using the coffee table as a pad for my note taking. Casandra sat in the overstuffed chair next to me as we began to get to know one another.

As we began our relationship, Casandra admittedly and insecurely stated, "We're dysfunctional. I'm kinda' mental." She wondered whether or not the story of her family could possibly enlighten anyone else. She believed that they have

just done what they have to do in order to survive their circumstances. There hasn't been anything heroic about the techniques they have used to cope with the circumstances. In fact, she clearly doubts her sanity and the functionality of their family. I assured her that I appreciated her willingness to participate in the studies; we all have our shortcomings, and I was eager to get to know her family.

In the beginning of our conversations, Christopher described himself to me and listed his characteristics, qualities, and preferences. He will respond to all of the following names and nicknames: Christopher, Chris, and Jones. There was talk of an X-box, Pokemon, and baseball. He even showed me his Pokemon card collection, and stated that he planned on keeping one of them. After all, it was holographic (3-D). He owns a dog named Diamond, which is a chow. His other dog is a German Shepard; the shepard is called Chewie.

Christopher celebrated his recent birthday at CiCi's pizza, where he ate a ton of pizza in order to show off, according to his sister. Christopher plays the violin and will have an upcoming orchestra concert that he invited me to attend. He proudly ran to get his instrument so that I could see it. He refused to play it at this time. He appeared flattered that I requested to hear him play. I was disappointed that I couldn't make the date for his concert, due to a conflicting schedule.

While waiting for their mother to finish cooking supper, the kids began a tour of the house with me. Casandra joined us periodically in between stirring the chili in the kitchen. Our tour began in the long wooden hallway that is lined with photos. The kids took the pictures off the walls and explained each picture to me,

identifying the people in the photos. Many of the photos were from years ago. There were several times when their mother had to help them recognize the faces in the pictures.

They pointed out pictures to me from when Christopher was younger and his eye did not droop. Then, they showed me ones where the drooping became apparent. Christopher then retrieved a photo album and began to go through it as well. I was entertained and emotionally touched as the kids joked and chided one another about the pictures and the good times they recalled from the photographs.

The house was very modest, and not neatly organized. It looked very lived-in. The kids showed me the rooms with clothes scattered about, and mattresses on the floor in several of the bedrooms. It was an old house, but big enough for all of them. The feel of the wooden floors and pictures around seemed homey to me. Colored curtains separated some of the rooms where a door must have once existed. It was the apparent love in this house that allured me.

In the background, I heard Christopher's mom call out, "Ya'll come and fix ya'll some food." A curtain hung down and separated the living area from the kitchen in place of a door. She had cooked chili and beans with rice. I followed suit and got a bowl and trailed the children back to the living area to eat. Casandra had graciously invited me to join the small family for supper. The kids retrieved a box of crackers and offered me a sleeve of crackers. We sat next to one another on the couch and shared the snacks between us.

Chris and Cassidy teased their mother about her fancy meals and cooking as we all sat together and laughed. The small family unit often joked with one another throughout our times together. The informal family structure made me very comfortable as they shared their history with me over a bowl of chili.

Christopher's black skin was covered in light brown skin spots on his hands, arms, and basically everywhere. Some of the spots were raised bumps. His right eye drooped distorting the shape of his eye. The discovery of his illness was at a very young age. I was still not sure at this time, what illness Christopher actually suffered from. "I think they figured it out when I was four," he recalled. The spots are referred to as café-au-lait spots. Christopher's condition is known as Neurofibromatosis. His mom said that it is Type 1. "At least I think his is type 1. I don't think his has advanced to type 2," she stated hopefully. All of the family members have some marks on their skin. His mother has three on her. His sister has several as well.

According to my later research, neurofibromatosis is a genetic disorder that causes tumors to grow on the nerves anywhere in the body at any time. The diagnosis of NF-1 includes two or more of some of the following symptoms: six or more café-au-lait spots, two or more neurofibromas (tumors that grow on a nerve), freckling in the armpit or groin, severe scoliosis, a tumor in the optic pathway, or a relative with NF-1. NF-1 is the more common of the two types of Neurofibromatosis, occurring in about 1 in 4,000 people in the United States, according to Neurofibromatosis, Inc (Neurofibromatosis, 2004). The disorder is not contagious, but affects both sexes and all races and ethnic groups. There is

no cure for the condition. The tumors can be surgically removed, but could grow back in greater numbers.

Christopher originally visited the doctor for congestion, since the marks were not a concern to his mother at that time. He had 27 marks at birth. The doctor asked if they had ever seen the marks before; his mother replied that it ran in the family; with that knowledge, it didn't go any further. The assumption was that the marks were simply birthmarks. The first time his uncle saw him receive a bath he said, "He looks like a chocolate chip cookie," Casandra interjected. His uncle still calls him "chip". Christopher seemed to like the nickname. He shook his head yes with a smile.

Christopher was originally referred to a cancer center in Houston. He went to that hospital for two or three visits. His mother then switched him to a children's hospital. They have remained under the treatment of the children's hospital and its doctors ever since that time. In the beginning of his illness, the tumors were not cancerous. His mom tried to recall, "I can't remember what came when. I think just yearly check-ups."

When Christopher reached the age of six or seven, his eye began drooping. A benign tumor was found in the socket of his eye. He experienced another eye surgery at the age of seven or eight. Once again, at the age of nine or ten, Christopher underwent a third eye surgery. The tumor would typically grow back within a year to a year and a half.

The surgery entailed using a ligament from the side of his leg to make a sling to hold his eye up. In a couple of months, the ligament started pulling his

eye upward. His sister, Cassidy flipped her eyelid up in an effort to show me what it looked like. Christopher laughed and did not seem bothered by such descriptive antics. Yet another surgery took place to correct the eye position.

Each of these surgeries required a somewhat brief hospital stay. They would go to the hospital in the morning. The surgery would take place, and then Christopher would remain in the hospital for overnight observation. His mother usually stayed at the nearby Ronald McDonald House, or in a motel. The Ronald McDonald House is a large house where the families of hospitalized children can stay for a nominal fee. In exchange for the stay, the residents are required to perform some household chores.

Christopher has seen his share of neurologists, ophthalmologists, and plastic surgeons. As for his vision, he sees 20/20 in his left eye. His right eye functions at 20/200. The corrective lens improves his sight in the right eye to 20/100. Casandra explained a number of unfamiliar terms to me referring to her son's eye condition. Among the terms were glaucoma, and amblyopia, which she described as the lazy eye. Ptosis is the drooping of the eyelid. In reference to myopia, she admitted, "I don't know what it is." She retrieved the medical book glossary to search for definitions.

Christopher wears glasses to protect his good eye. He suffers from decreased peripheral vision. The doctors also believe that he has no depth perception. Mom stated, "That's what they say. I think he does." Christopher is at risk for retinal detachment, according to his mother. Christopher questioned, "What?" His mother's response made it evident that she had previously

discussed this possibility with Christopher. “Remember when I told you that?” reminded his mother. “You’ve got to hurry and let me know if there seems to be a problem with your eye. We’ve only got twenty-four hours to get treated for that.”

“When I was twelve, that’s when they found the brain tumor.” At that time, Chris’s peripheral vision was decreasing. His MRI indicated there was a brain tumor. Within a year, Chris underwent three brain surgeries. Humangoblastoma was the term that was associated with the discussion of the brain tumor. The first surgery was actually a biopsy. They went in to get a piece of the tumor. They were unable to get it all; it was “...down in the brain” according to Casandra. The pathologist in Galveston didn’t know the nature of the tumor. After conferring with MD Anderson Cancer Center, the doctors concluded it was “absolutely necessary to put him back through it,” remembered his mom.

Casandra recalled the helpless feeling resulting from her lack of knowledge, and from the doctors’ uncertainty as to the nature of the tumor. It was extremely difficult to not know what was best for her son, or the best treatment plan. When she realized that the doctors felt it was necessary to proceed with another surgery, she was willing to do whatever to try and help her son. Still, there was an enormous amount of fear of the unknown.

In the second surgery, it was discovered that the tumor was the size of a sweet pea. Once again, the surgeons did not remove the complete tumor. “They didn’t want him to wake up different than when he went to sleep,” elaborated his mom. There was a risk of mental retardation. Finally, on the third surgery, the remainder of the tumor was excised. At that time, a decision was made to

undergo radiation treatment. There were daily treatments for a total of 36 treatments. Christopher stayed in the hospital for seven weeks.

Casandra recalled the events following her son's third brain surgery. This surgery caused a great deal of uncertainty since the remainder of the tumor was finally removed. It was unclear what Christopher's condition would be following the surgery. She had to go to the motel to get some sleep. She remembered stopping to get food for Chris at the store. She purchased grapes, pineapple chunks, sprite, and a breakfast burrito.

When she returned to the hospital, she discovered Christopher sitting in his bed Indian-style with gauze wrapped around his head. He ate all his breakfast and was watching Bambi. In the pediatric intensive care unit the day following surgery, Christopher asked his mother, "Moma, what am I waiting on?" Several comments later, he complained, "I missed my Scooby Doo."

The doctor said that Christopher seemed stable and could attempt walking. He put on his socks, and with IV's in both hands, set off on his small journey. He played and was able to get around well. He did need help with his shirt and brushing his teeth. Christopher contrasted the bounce-back with the first surgery, where he, "didn't want to do much, I just sat there." After experience, Christopher realized the faster he gets up, the faster he goes home.

I was once again amazed at the resiliency of a child his age in dealing with the difficult circumstances at hand. Chris spoke of the surgeries matter-of-factly. It was obvious that he desired to have the most normal life that he could possibly

maintain. In my estimation, it appeared that he was doing an excellent job in that regard.

During Christopher's extensive treatment, his mother would come home on the weekends to see her daughter who she refers to as her "other baby". She would try and spend quality time with Cassidy to stay as in touch as possible with the child's needs. It was the best she could do under the circumstances. The family still missed each other despite these efforts. As much as quality time is promoted, quantity of time has merit that cannot be denied. The family continued to do their best to deal with the less than desired circumstances. Casandra was thankful that Cassidy's grandparents were available to keep her during this time. She acknowledged that some families in today's society would not have any relatives nearby to assist in such a time of need.

During the week, Christopher and his mom stayed in a motel. She brought the VCR, Nintendo, microwave, radio, and she thinks perhaps her coffeepot. They would go to the hospital for the daily radiation treatment. The family lovingly bickered as they discussed the details of their recollections of that time frame. There was talk of walks on the beach, and Cassidy throwing her brother in the water. He was afraid of the jellyfish. Christopher missed home when he was away for such an extensive period.

When I inquired about Cassidy's concern about her brother, I discovered that she slept on a palette on the side of his bed for three nights when he returned home, according to Cassidy. Her brother corrected her and said she slept there for three weeks. "He had the nerve to put me out of the room," she

chided. "I kept stepping on her," he refuted. "I'm concerned about him," she caringly admitted.

Christopher was out of school for two months after his surgery. When Chris and his mother returned home, Casandra says, "It was back to reality." The daily responsibilities do not end simply because you have a child that is sick. Some people seem to think that the world stops for those people who are undergoing extensive trials with a chronically ill child.

This close-knit family shared with me that this misconception is not the way it works in reality. A single mom is still a single mom without the desired support of a loving spouse. Siblings of the ill child are still expected to continue on in school as if their world at home remains normal. The children are shuffled, if they are lucky, from parents to grandparents' or friends' houses. They are expected to deal with this instability without any sense of displacement, and without any sense of worry about their sibling or the fear of their life. Issue after issue surfaces that those of us who are not privy to the world of caring for a chronically ill child are simply never aware. Although I gathered this information from observation and interview facts, this family never complained of or wanted sympathy for the struggles that they have experienced. They simply take the challenges as they come. They seem to deal with their problems with resiliency and humor.

Casandra's Interview

Chris's mom, Casandra, has a physical condition that hinders her ability to do a great deal of physical labor. During the course of our interviews, we had to

schedule around a surgery she was having performed. Casandra suggested that I come over and assured me that she could “still talk to me from her bed”. When the time came, she was not feeling as well as expected, and we rescheduled for a more suitable time. I was amazed at the willingness of this mother to allow me to not only share the most intimate details of her family’s struggles, but also enter into her personal world at such a vulnerable state. I found it to be too intrusive, but was touched by her willingness to help in any way possible.

Casandra’s own physical problems made her ability to adjust to her son’s condition even more strenuous. I noticed she had trouble getting up from the chair once she got settled. Casandra mentioned her inability to do some daily chores, but in general was able to accomplish the necessary duties of her life. I appreciated Casandra’s forthright attitude and willingness to be transparent.

This mother is evidently very strong. She has dealt with her son’s illness without the support of a husband. She is accustomed to the sole responsibility, but admitted that there were times when she would have benefited from having someone to talk to. She felt that others could support mothers in her situation by talking with them to prevent the feeling of isolation.

Chris’s mom obviously valued communication. Casandra is careful to assure that Christopher is aware of what procedures the doctors will perform. “Anything they do, I have to talk to him, so he will know,” she commented. She finds this honesty about his medical condition is important for Chris and has always operated with this in mind when dealing with his illness. During the

interviews, there seemed to be no hesitancy on any family member's part to share their feelings or the whole truth about an incident.

There were times the family mentioned that Chris and his mom stayed at the Ronald McDonald House. Casandra felt the Ronald McDonald House is a nice place, but she did not like the stringent rules. Casandra recalled an incident when the person on duty would not let them leave before daylight due to a house rule. Christopher had a six a.m. surgery. He was unable to get there on time in order to get prepped for his surgery. That experience was the last time they stayed at the Ronald McDonald House.

Since that time, Casandra made arrangements through Medicaid to stay in a local motel when her son was hospitalized. Both she and Chris seemed to favor these accommodations. It offered the family some freedom and flexibility with their personal schedules, allowing them to tailor their timetable around his treatments.

Casandra's typical schedule when Chris was receiving radiation treatment for seven weeks was fairly routine. Medical transportation would bring her from her hometown to the hospital. She would check into the motel on Monday through Friday. Chris received radiation treatment everyday.

Casandra spent a great amount of time at the hospital with Chris on the weekdays. She would try to help him pass the time. There was not much else for them to do since they were away from home. She felt there was too much time to think and worry. She advised other families to try and focus on the day at-hand and not worry about the future. She admitted that there were times when this was

easier said than done. From her perspective, all of the worrying still did not affect the outcome. She might as well make the best possible situation out of the actual circumstances. Her current mood often affected the way she perceived her reality. Times just seemed better when she would "...go with the flow". Otherwise, she felt at times that she might go insane. She is still not sure whether or not she is sane.

Casandra's weekdays also consisted of visiting the hospital classroom with Chris. She accompanied him as he met with the teachers and completed his schoolwork. Casandra was appreciative that the hospital school took responsibility for switching his school district and enrolling him in the hospital school. This action allowed her to focus on her son's condition, rather than being concerned with bureaucratic details. The school then switched him back to his home district when he was discharged from the hospital. The schooling during the hospitalization permitted him to stay as current on his work as possible, considering his physical condition. It also gave him something to occupy his time and mind while in the hospital.

On the weekend, Casandra would return home and see her daughter who had been staying with her Casandra's mother. It was a difficult balancing act between managing the needs for her children. This situation caused her guilt sometimes. She occasionally reminded herself that she was doing the best she could; she was only one person; she could not be two places at once. There were many times when she longed for that skill.

Casandra is thankful that she had family that lived locally and was able to assist her with Cassidy's care. Since Chris was hospitalized for such lengthy periods, it would have been impossible for Cassidy to attend school if the family had not been able to step in and assist with this highly important, but practical matter. Casandra is aware that she was blessed in this regard. Her mother has been a great support throughout Chris's illness.

Financially, this family serves as a reality check for our system and the nuances within it for a family with a child with a chronic illness. Casandra held a full-time job from which she believes she was wrongly fired. The case involves maltreatment of individuals at a nursing home where she worked. A lawsuit is pending in which she expects to receive a large sum of money.

Meanwhile, her family is essentially poverty-stricken. The family receives SSI for having a child with an illness. Medicaid has covered Christopher's hospitalizations and treatments due to the family's financial constraints. Medicaid covered the transportation to the hospital and provided the motel room while his treatment took place. In addition, she would receive money orders for spending cash each day. Casandra acknowledged, "It's a shame to say it, but it seems like you're better off when you don't work. When I was working full time, our food stamps were dropped. When I go to work, I can't make ends meet." She proceeded, "There's something wrong with the system when you can sit on welfare and make it, but if you work, you can't."

We talked for a while about the system and its inability to assist in the way that she felt would actually encourage people to work for a living. She liked

working and providing for her family. She depended on her job and the income that it provided. When she was wrongly fired, she felt that she should pursue a lawsuit to expose the company for ill practices that were taking place. It turned out that being out of work turned out to be more lucrative than when she was working. Casandra continued to express distress over these facts.

Casandra is expecting a large sum of money when the lawsuit concludes. She already has plans for a new house and better environment for her children. She is also attending school to further her career opportunities. Although the circumstances surrounding the lawsuit were unfortunate, it appears that this is a step to financial security for this family who seemed to have no other successful financial alternatives previously.

Christopher's Interview

Christopher, nicknamed Chip, reminds me of a puppy dog with his sweet demeanor and attitude. The eye that droops is rather endearing as you see the kindness and strength that comes from within. His personality is very upbeat. He believes in dealing with life in a positive manner; this attitude is apparent from his contagious smile and joyful spirit.

"We wish you a Merry Christmas" played in the background as Chris and I sat together on the living room sofa for his interview. Dressed in blue jeans and a t-shirt, this thirteen-year-old boy appeared both comfortable and confident. I thought of the practical experience and hardships beyond his years that this young man has undergone; many people will never face these fears and realities in a lifetime. I was glad that this Christmas would be spent at home with his

family. I presumed that some other occasions had been dampened due to his hospitalization and separation of the family members. He agreed that he was looking forward to the holiday at home with his family.

Christopher feels that it is important for the family to stay close during times of illness. He was thankful that his mom was able to be with him for most of his hospitalization. He missed both his friends and family when he was out of town at the hospital. The numerous surgeries and the extended radiation treatment meant that he was away from home for quite some time and on various occasions. Due to the hospital's distant location, he was prevented from seeing his sister and other extended family members, except primarily on the weekends. Chris never mentioned his father, or the lack of his involvement in his life. I am uncertain the details that surround that reality.

Chris admitted to missing his sister, with a sheepish grin. The two siblings appear to have a positive and close relationship. There is a great deal of teasing between the adolescents during the various interviews. He was sorry that his time in the hospital has kept the family apart, but realized it was out of his control.

It is evident from talking to Chris that he has a number of friends. He attends public school and mentioned a number of his friends. When he showed off his pictures to me, he pointed out his peers. He spoke fondly of his birthday party at the local pizza joint. Christopher appeared self-important as his sister teased him about eating a huge amount of pizza. His chest swelled with pride as if he had really accomplished a great feat.

Chris in no way complained of his current living conditions. He did, however, seem excited about the possibility of affording a new house. He and Cassidy began to dream aloud of the things they would purchase if they had a huge sum of money. It was the same attitude that prevails when you allow yourself to imagine what you would do if you won the lottery. He is aware that his mother might be receiving funds from a lawsuit relating to her wrongful termination.

When hospitalized, Chris attended the hospital classroom. He was re-enrolled in the school district in the town where the hospital was located. The hospital took care of the details of arranging the school enrollment. Chris would simply go to the classroom in the hospital and do his work that the teachers assigned. He liked this arrangement fine.

The first time that I met Chris was in the hospital classroom as I was serving as a volunteer at the hospital. He was working side-by-side with the teacher on an assignment. I was impressed with his attitude and willingness to work although he did not appear to feel well. When Chris was unable to get out and attend the classroom, the teachers would come to his room for instruction. He preferred the self-paced work, but missed his social life at school.

Chris did enjoy getting out of his room and attending the various activities that the hospital offered for pediatric patients. There were times when he would watch a movie in the playroom or play bingo with a group of other kids. Art projects were always at hand if he desired to participate. Chris tried to make the

best of his time while hospitalized. Yet, his primary goal was to do whatever he could as quickly as he could to go home.

Christopher spoke of the hospitalizations and his accommodations when he was going back and forth for treatments. Christopher enjoyed the Ronald McDonald House when he was younger. He shared that now he doesn't prefer it, because his mother has to follow him around wherever he goes. He has to hurry to take a bath or whatever he is doing, due to the fact that a child cannot be left unattended. "I couldn't stay in the playroom without her there," Christopher said in a typical teenage style. "He was seven or eight, not a toddler," his mom adds. "It got boring with mom following me around," he admitted.

Chris preferred when he and his mother stayed in the hotel. He was able to play his Nintendo at that location. He appreciated the freedom to explore the place, within limits, of his own accord. It is evident that although Chris loves his family, he values his independence. He has been facing these life challenges for a number of years. Perhaps he feels more capable of handling himself in various situations. Perhaps it is just typical teenager's search for independence.

It was difficult for me to fathom that the young man before me had experienced three brain surgeries within the last year, and was yet willing and able to conduct an interview with me now. His strength and perseverance are amazing to me.

Chris advised family and friends to treat a family undergoing a chronic illness like you would want to be treated. He urged others to remember that the individuals are still the same people, and that they still need friends, even if you

don't know exactly what to say. This makes me think "The Golden Rule" sometimes is easier said than done.

Cassidy's Interview

Cassidy is a sociable and likeable 15 year old. Her eyes danced as she teased her brother on a number of occasions. She was dressed casually in jeans and a sweater as we talked about her family and how they deal with her brother's chronic illness. Cassidy seemed open and willing to share her opinions with me.

It was very apparent in talking with Cassidy that she has a deep love and concern for her brother. She does not ever recall any ill feeling towards her brother or the extra attention that he has received due to his medical conditions. She does realize that the extended hospitalizations and treatments took away from her time with her mother and brother. During those times, she stayed with her grandparents. Cassidy's mom made an effort to call her daughter each night. Cassidy realized that her mother needed to be with Chris during those times. She did miss her mom and brother a great deal. She also worried about him and his well being.

Cassidy's response to her mother saying that she would come home on the weekends to see her when Chris was in the hospital was humorous. She jokingly replied, "Those were the days." Cassidy recalled going on an occasional weekend to see her mom and brother; the family would take excursions around the town. She mentioned a trip to the beach where "I fell in the sand and Chris tried to pull me out." She laughed that Chris was afraid of the jellyfish when she threw him in the water. I enjoyed listening to the various renditions of the stories.

Cassidy recalled the time when her mother and brother were gone for the extended hospitalizations. In the past, the two of them would go for several days when a surgery took place. Chris's most recent brain surgery was an exception. It was the third brain surgery of the year. Cassidy said after the surgery the doctor decided that Chris needed weeks of radiation treatment. This occasion is when she stayed with her grandparents.

She did not recall any of her grades dropping in school; she acknowledged that it was more difficult to concentrate with the added worries and unusual life circumstances. She wished she could have lived where she could go to school in the same town where the hospital was located. It was difficult to be away from her mom and brother for so long.

Cassidy was able to talk to her friends at school about her concerns for her brother. She relayed general stories of her friends and their interactions. I was glad to see that she had some social support to help her through the difficult emotional times. In fact, at the conclusion of our interview, or rather, concluding our interview, Cassidy's best friend came by to retrieve her for a friendly girls' get-a-way.

CHAPTER V

RESULTS, RECOMMENDATIONS AND CONCLUSION

The intent of this chapter is to present an analysis of this research project. The chapter includes answers to the research questions that guided the study. The findings of the study are organized and presented as emergent themes. A discussion of the research findings and process is offered. Concluding the chapter are recommendations for further research in the examination of families coping with a child suffering from a chronic illness.

In order to meet the objectives of this research project, the researcher studied the everyday lives of families facing one of the children suffering from a chronic illness. The researcher used the generic approach that entails investigating different illnesses rather than one common illness (Meleski, 2002). This approach was used in an effort to understand and appreciate the commonalities that families with children experiencing chronic illness face. The children in the research project each have a different diagnosis, and yet are able to illustrate the common needs and experiences across the various groups.

RESPONSES TO RESEARCH QUESTIONS

1. What are the perceived needs of the parents and children in families coping with a child with a chronic illness?

The following list provides insight into the perceived needs of the families studied. The listed needs are further detailed and examined in the subsequent section that features emergent themes.

Information:

- The respondents often mentioned a need for accurate, prompt and complete information regarding the child's diagnosis, care, current condition and prognosis.

Practical Support:

- Practical support is seen as a necessity. There are numerous activities, chores and duties that are overlooked due to the necessity of taking care of the important and immediate needs of the ill child. Examples such as driving, caring for other sibling, meals, mowing the lawn, running errands, and babysitting were all cited. One mother offered, "People, even family members, told me they were too 'afraid' of my daughter to watch her for an hour for me so that I could take a shower without worrying about whether she is being attended to." Ray (2002) reported that the technological care of chronically ill children often intimidates potential caregivers.

Emotional support:

- Emotional support for the members of the family was an essential ingredient in their coping process. The extenuating and stressful life circumstances made existence almost impossible lacking emotional support.

God's Help:

- God's help and prayer was mentioned repeatedly in the families' personal lives, as well as with respect to their requests from others.

Financial Needs:

- Financial needs were a great burden on the families. The sizable hospital bills and medical expenses added to the already burdensome situation.

Career Needs:

- Cooperation from the parent's workplace concerning time off during their child's extended illnesses and hospitalizations was beneficial.

Medical Care:

- Families seek adequate medical care from various medical facilities and doctors. Researching options was a monumental task.

2. How are the everyday lives of the various members of the family affected by the illness?

- The members of the family of a child suffering from a chronic illness are greatly impacted. Their everyday life is especially affected during times of lengthy hospitalizations. This inordinate amount of time spent

with a hospitalized child is often unexpected or planned for in the lives of the family. Suddenly, a child is ill, and everything else in life fades to the background as the paramount needs of the ill child are addressed.

One respondent recognized, “Out of necessity for her survival, everybody had to do their part.” Relational struggles, along with other issues dissipated, as he realized the child needed the support system around to complete her care.

- The everyday lives of parents in this research project were severely altered. From practical aspects to emotional facets, each family member is undeniably impacted when a child in the family is chronically ill.
- From a practical side, the work and time schedule is affected immensely by the lengthy and/or repeated hospitalizations. Examples from this study confirm the previous research (Beresford, 1994). In the one parent family, the mother was the sole parental support for her son. She was no longer working and was able to spend the necessary time traveling to the hospital over an hour away for repeated brain surgeries and radiation treatments. Over a month was spent away from her other child. Fortunately, she was able to visit with her daughter and maintain a close relationship.
- In the divorced family, both of the parents, as well as the mother’s boyfriend, adjusted their lives to accommodate the needs for the children at the stress-point time of hospitalizations, and at home with

the extensive follow-up treatments. The mother took extensive time off work to spend time with her daughter in the hospital. After the hospitalization, she eventually returned to work on a part-time basis. The father also took off a month from work in addition to numerous short periods of time off work in order to assist with his daughter's care and to maintain his own emotional well-being. The mother's boyfriend was not working and served as the primary caretaker for the sibling while her sister was repeatedly hospitalized.

- In the married family, the mother had her own business that allowed control over her work schedule. Since her cosmetology salon revolves around appointments and walk-ins, the mother was able to accommodate the family's needs throughout her daughter's illness. The father was on-call and was available sporadically, or as needed. His employer was accommodating to his needs for time off.
- The well siblings' lives and schedules are remarkably affected as well. The children all mentioned worrying about their sick sibling. There were times in each of the studied families where the ill child's condition was considered critical. The well children did not seem to talk a great deal about their fears to their family. They did mention having some friends with whom they were comfortable sharing their feelings.
- The siblings of the sick children were also expected to carry on a regular school schedule despite the condition of their sibling. Several of the siblings did not know if their teachers were even aware of their ill

sibling's condition. The well children were often carted back and forth to the hospital each day and were required to continue to complete their routine homework and school responsibilities. After the emotional hospital visit, the siblings in the study stayed the night with either grandparents or another caretaker while the parent remained at the hospital. The siblings rarely had the overnight support or regular routine that their parents offered.

- In this study, all of the well siblings were older than the ill child. Protection of the younger ill child was apparent. One chronic child appreciated her sister sharing her friends with her. Another big sister recalled sleeping at the bedside of her brother for days after returning from the hospital. Still, the third sibling expressed her concern for her sister through crying each time she visited the PICU to see her sister.

3. What strategies do the family members use in dealing with the life changes?

Boyd & Hunsberger (1998) outlined strategies used by chronically ill children. The participants in this study employed many of these same strategies.

Distraction:

- One sick girl used dreaming to distract herself from her reality. The chemotherapy treatment made her feel like she was dreaming. I asked her what she dreamed of and she responded, "I dreamed I was out sitting on a boat and playing cards with my mommy."

- One child remembered she dreamed that she was playing sports when she was sick in the hospital and unable to be active.
- In her own hospital room, one patient spent time coloring and drawing. She tried to distract herself by focusing on topics other than her physical condition. She envisioned her friends and how she previously spent her time in school: “It kinda helped me soothe my mind. I wouldn’t be like, what’s gonna’ happen next?”
- In talking of the procedure of getting an IV, one girl explained how her mother distracted her so she wouldn’t watch: “My momma just turns my head.”
- A boy watched his favorite cartoons to keep his mind occupied. While watching Bambi, he complained, “I missed my Scooby Doo.”

Seeking social support:

The families all commented on the support or lack of support from other people.

This was valued from all respondents.

- One mom looked forward to the movies, food, and wine that her friend would bring: “It was a nice escape when I couldn’t. Nobody else did that for me.” The emotional escape of watching the movie demonstrated this mom’s usage of an emotion-focused coping strategy (Beresford, 1994).
- One mother used the Internet to interact with other families experiencing similar circumstances.

- Extensive references were given from the various family members regarding the support of their friends and church members.
- The siblings all mentioned talking to their friends about the ill child's condition. Parents also mentioned talking to others as a means of coping. The frequently ill children also valued their friendships and familial relationships.

Emotional expression:

Emotional expression was indicated throughout the interviews, particularly in regards to talking, crying and expressing oneself through art.

- A sister acknowledged, "Me, I never make it. I cry every time, because I have issues of my own. That's the way I deal with things. I don't talk about stuff too much."
- All of the sick children, in addition to several siblings, revealed they used art to express themselves emotionally.

Submission/cooperation:

One of the hospitalized children realized that his cooperation with the hospital routine would allow him to go home sooner.

Avoidance/resistance:

An example of resistance was repeatedly mentioned with one girl who refused many of her medications. Compliance with her nutritional requirements was also a battle for this family. Her mother remembered, "I hated forcing medications down her that she didn't like while she screamed and thrashed to try to not take them."

Seeking information:

Numerous examples were listed from families in reference to the importance of seeking necessary information. Frustration and fear resulting from a lack of information were acknowledged.

Day-by-day mentality:

The families were so consumed with the realities of their current circumstances that the far-reaching implications of their situations were often not the focus of their energies. The families' attitudes reflected a day-by-day emphasis.

Maintain normalcy:

An effort to maintain normalcy was exerted in the families. The members recognized that their lives were not normal, and yet strived to hold onto some hint of normalcy when possible. This was evident in the attempt at maintaining work and school schedules for the members of the family not at the hospital.

Seeking best care and education for child:

The parents learned about, searched for, advocated and implemented the best possible care for their children. This was evidenced in their search for optimal health care and educational opportunities.

Talking to one's spouse:

Brown and Hepple (1989) noted the importance that parents place on talking to one's spouse as an effective coping strategy. In this study, one respondent shared how he and his wife supported each other in times of weakness. The other parents were either single or divorced.

Restructuring the circumstances using humor:

Brown and Hepple (1989) related the importance of humor as a coping strategy.

Several participants used humor to cope with their circumstances.

Focusing on the positive:

Brown and Hepple (1989) acknowledge the importance of a positive outlook in the coping process. One daughter reminded her mother of this important point:

“Face the bright side mom.” When her mother asked, “What’s that?” she replied, “The other side of the mysterious darkness.”

Support from extended family:

All of the families mentioned the roles that the extended family played. In two of the families, it was the grandparents who cared for the sibling when the ill child was hospitalized.

Formal support:

Formal support utilized by the families included counseling, church groups, and an Internet support network. This type of support was accessed less frequently than that of informal support. One study revealed that the coping strategy of formal support was often a last resort (Boyd & Hunsberger, 1998).

- Only one of the families joined the national support organization that supports their child’s illness. Such groups offer information, conferences, summer camps and connections for local support groups.
- One mother expressed willingness for formal support, if informal support was not available. She did not feel that her family had needed formal support, due to the extensive family and friends.

- One mom used the list serve posted through the Joubert Syndrome Foundation. Through this medium, she communicated with other families that were coping with the same illness.
- One mother sought professional counseling at the crisis time of diagnosis.

4. What effects did the illness have on the individuals and family functioning?

- Family functioning is affected when the individual members are each independently impacted significantly, which seems inevitable in the experience of a child member suffering a chronic illness. The families no longer have the time to nurture the important relationships that they hold dear to them. It is of paramount importance that the members do have someone to talk to and provide support.
- The researched families commented on the adjustments in their family structure. There was a change in the roles within the family. A mother who previously worked was now the constant care-giver to the ill child. Siblings who previously spent hours of free time in the afternoons were now required to spend hours visiting the hospital. Children who were previously well were now diagnosed and coping with an illness that will persist for a long period of time.
- One mother commented on her adjustment to the illness and the implications of it by stating, "Was there any adjustment? I don't recall having that luxury. I got thrown into the situation with no real

preparation, but there is no preparation for taking care of a sick child with whom you have an emotional attachment. I got good at it, but never liked it.”

- No one begrudged the child for the inconvenience. To the contrary, the love of the family surrounded the child. Each member wished they could take away the unfortunate circumstances. The parents often felt helpless during this time frame.
- In reference to adjustments in lifestyle and caring for his daughter, one father referred to the difficulty of keeping up at work and having to give up work assignments. Both fathers told of the balance between visiting the hospital and trying to maintain their work. The fathers spent significantly less time than the mothers at the hospital, due to the commitments at work. Both men mentioned their employers’ willingness to accommodate the necessary time off. The men were appreciative of this consideration.
- When the mother donating her kidney to her daughter was hospitalized, her daughter commented that the mom was alone and pale in the hospital room. The other family members were busy taking care of the daughter receiving the transplant, as well as her other daughter at home. This left the mom all alone and unattended. The mother, previously serving the role of primary caretaker, was unable to fulfill this role; rather, she was fighting to maintain her own diminishing health.

- These findings confirm research that states that parents of disabled children consider themselves to be isolated and lonely (Bradshaw & Lawson, 1978; Melnyk et al., 2001). According to Quine and Paul (1991), social isolation can be one of the most complex factors of caring for a disabled child. A quote from a mother in the current study depicts the sad reality: “I don’t have any real friends anymore. They slowly drifted off with each child I had, and faster with each disabled child, and faster still, as they got sick, and one died. Friends just don’t want to deal with these issues on a daily basis. And frankly, I don’t think the same way other people do anymore. I certainly don’t have the same priorities, and I’m incapable of maintaining ‘small talk’ anymore. I have very deep emotional scars that are hard to hide, and people think they are unattractive.”

5. What are the perceived obstacles or difficulties that the family members attribute to the chronic illness?

- The perceived obstacles as seen by the parents included, but were not limited to the following issues: scheduling constraints, financial burdens, inadequate accommodations, extreme emotional adjustments, feelings of isolation, lack of knowledge or information, relational issues resulting from differences in personal coping styles, and changes in lifestyles.
- The obstacles mentioned by the chronically ill children in the study included some of the following: loss of privacy, feeling ill, boredom,

painful procedures, missing their friends and family, lengthy hospital stays, and specific limitations of the illness. Some of the same stressors were noted in a related study (Boyd & Hunsberger, 1998).

- Siblings mentioned obstacles related to changes in lifestyle, such as: living without their parent, driving everyday to the hospital, maintaining their schoolwork despite the stress, seeing their sibling in an extremely disturbing condition, and worrying about their sibling and parents. Other inconveniences were cited, such as one ill child's reluctance to take her medicines causing the family to run late in the mornings.
- There is heartfelt anguish in the following description of obstacles. As one parent noted, "Having a child with a disability is something you can learn to adjust to over (a long period of) time – it's not what you want, but you get used to it and learn to deal with it. But you worry all the time with a child who is sick - and that is a different kind of stress; I think it is a worse one. The obstacles are these.... you can't just leave a disabled child with any sort of babysitter, and you can't leave a sick child with hardly anyone at all. My daughter has had two babysitters, ever, in her whole life. I just can't trust them to care for her the same way they would just any other child. No baby sitters means less fun. I also haven't been able to leave her at just any day care, and dealing with day care is very difficult because they tend not to pay much attention to her - and she needs more than other children her age. After school and summer programs often will not take her unless I am

the aid, or I provide one. All this stuff was every day life when she was 'just disabled,' and much, much worse when she was sick. Nobody could take care of her then, so I had to stop working for two years. I was very fortunate that I wasn't fired and that I was able to keep my health insurance."

6. How do the individuals and family function during this stressful time?

- Individuals and families vary in their responses and style of functioning during stressful times such as a child suffering from chronic illness. Even within this particular situation, certain time frames are seen as more stressful and seem to warrant a more imminent response from the families. The researcher noticed that periods of hospitalization seemed particularly stressful emotionally to the families. The time of diagnosis was also referred to with great emotionality. The parents seemed to function on over-drive for the periods of hospitalization. Multiple references were made to the fact that they had "no life" during this time frame.
- When the families returned home, despite the at-home care and the numerous life changes, a relief to be back to an attempt at normalcy was still noted amongst the members of the families. Support was still necessary. At-home health care and homebound teachers were seen as positive help when the families underwent this important transition.

Snowden and Kane (1987) recognized the need for support in the transition to home from hospitalization.

7. What strengths and weaknesses of the health care professional are perceived by the family in regards to aiding them in the adjustment process?

- The families repeatedly mentioned a need for practical amenities for the hospitalized families. Many of the patient's families are displaced for a period of time. A weakness was seen in the hospital's accommodations for the families attempting to spend time with their critically ill child or sibling. Areas for sleeping and waiting were minimal, and too small for the number of people. In addition, feasible parking and food were mentioned as areas of need.
- The children appreciated nurses who were happy. They had positive affect for the nurses who attempted to help them through a procedure such as a needle stick, rather than just continuing to poke until they got a successful stick.
- Weaknesses were revealed when doctors made human errors. In addition, there were times when staff was neglectful of the patient, according to the families. The incident where the child fell out of the ICU bed is offered as an example.
- Another weakness that the families perceived was lack of communication or communication skills when giving important health information. The father who humorously, but painstakingly, reenacted

the scene when the doctor informed him of his daughter's Lupus diagnosis quickly comes to the mind of the researcher. There should be awareness on the part of the person delivering the important message as to the state of the listener. Simple communication or empathetic skills could offer assistance in this respect.

- Appreciation was expressed for those doctors who seemed to genuinely care about the patients and families. One father specifically recalled the doctor who apparently cared and stayed up all night to try and determine his daughter's diagnosis. This caring and empathetic attitude is an important factor to the patients and families during such a stressful time (Boyd & Hunsberger, 1998).

8. What recommendations or suggestions do the family members have for the organizations or individuals including health care professionals, educators, family members, formal support groups, friends, which could serve to help families coping with an ill child?

- The families requested more time permitted at the child's bedside while the child is in the hospital. The families perceived the time when they were required to leave the bedside as a convenience for the staff and not supportive of their needs. All of the parents in the study saw the time away from the bedside in a negative sense. Arguments were stated that pointed out the necessity of the parent's presence when the doctors were rounding; the parents needed to hear the pertinent and critical information regarding their child. One parent commented on the

unreliability of when the doctor would come talk to you and that there was a sense of uncertainty never knowing when you could even go eat, for fear of missing the important meeting with the doctor. The families felt that it would be more effective for them to be there to speak to the doctors at the time of rounds, which would assure their presence at the appropriate time. Studies on family-centered care support the notion of keeping the parents as involved as possible in their child's care (Caty et al., 1984; Hostler, 1991; Miles & Carter, 1985).

- Several other incidents relating to the fact that the parents were asked to leave the bedside warranted concern as well. One child fell out of the bed while in PICU and hooked up to numerous IV's and tubes. The family felt that incident could have been prevented had they been allowed to remain in the room. Another mother was asked to leave, but persisted until the doctor allowed her to stay in the room for the removal of a tube. She insisted on pain medication for her child, who was screaming. She was met with resistance as the doctor assured her the procedure was painless. Upon further trials, it was evident that the tube was actually still sutured to the child. The doctor was dismayed, as the sutures should have previously dissolved. What should have happened and didn't, was only countered by the fact that this mother advocated for her presence in the room and for her child's pain medication. Neither of these happenings would have occurred if

this mother had not persisted on behalf of her child. Parents should not be overlooked as the primary source of information for their child (Balling, 2001).

- Families were appreciative of the friends and family who supported them during their child's chronic illness. Practical assistance such as meal preparation was mentioned by all of the families. Meals at the hospital become both monotonous and expensive. Several of the children mentioned not liking the hospital food. A parent suggested, "Extended family could have helped out by sending gift certificates for restaurants, housecleaning services, lawn mowing services, etc. Even the hospital provides a debit card that money can be put on for the purpose of making cafeteria purchases."
- The families also expressed appreciations of gifts received. Suggestions for gifts for a family with a hospitalized child were given. A phone card would be a well-used gift. There are so many calls to make that the costs become prohibitive. Tokens or money for parking and meals would be appreciated. Snack baskets with the family favorites would be a nice piece of home, if the ill child is able to eat at that time. Reading materials, games or art materials to keep the children and parents occupied at the bedside would also be valued.
- Several other primary points mentioned by the families with regards to outside support were the prayers offered by others for their family. These prayers were from family members, church friends, friends, and

prayer partners, and chaplains at the hospital. The request for prayers of the family members was easily predicted after a number of interviews.

- Friends and family who visited and called were also vital in the emotional well being of the family. Several of the parents mentioned having something to look forward to when they knew that a certain person was guaranteed to visit each day. One mother added that even if the time frame was five to ten minutes, at least she knew she could look forward to their visit.
- Simple pleasures and gestures are greatly valued when the simplicity of life has been robbed from these families' lives. "Bring some old magazines, a book, the latest couple of newspapers for your friend to read in the lonely hours. Call and ask how your friend and the child are doing. Write e-mails or letters. Stay in touch. Let your friend know what is going on in the outside world and at work so they don't feel so disconnected," suggested one parent. Another suggestion was for volunteers to watch over the patient so that the parent could take a break long enough to go to the cafeteria.
- All of the female siblings felt that friends could help them and families like theirs by just being there for sharing.
- Educators are encouraged to attempt to understand the nature of a chronic child's condition. Patience with the ill child and close attention to their needs is important. Close communication with the parents will

aid in the transition of these chronic children back into the classroom. Parents' requests should be respected and the education system should offer assistance in determining which programs their child may be eligible for. There are programs that exist for children with disabilities; one of the mother's whose daughter had brain damage was unaware that such programs existed, despite her efforts to inform the school of her daughter's special needs.

EMERGENT THEMES

As the study progressed, themes emerged that were consistent threads of information from different participants. These themes have been extracted from the interactions, interviews, observations and information that the participants offered. The themes are further detailed by supporting subcategories. The emergent themes from the research project are detailed below:

Alarming Environment

This theme emerged as a recognition of the disturbing experiences that the families endured, ranging from the diagnosis of their child, to the fear of the child's death and the upsetting experience of seeing the child in an ICU setting with extensive medical equipment and tubes. The families' lack of power to change the situation is also addressed in this section. The alarming environment refers to both the sights and sounds of the environment as well as the emotional component of the experiences.

Diagnosis Dilemma

At the time of diagnosis, the parents mentioned a period of not knowing what to do or how to respond. In addition to a lack of information, the parents were faced with forming a new reality for their lives and their child's life. The initial shock and devastation were undeniable. Each family responded with intense emotions to the diagnosis. All of the families discovered the diagnosis after an extended time of uncertainty and repeated doctor's visits in search of the source of the problem. A clear cut, quick diagnosis escaped all of the families participating in this research project. There was a search, a discovery, and then the reality that would ensue over the newfound knowledge. It was the beginning, not the ending, of a new and revised life. The realization that coping is management of a problem, and not mastery of a problem became a reality for the parents at this time (Lazarus & Folkman, 1984). Parents and families of chronically ill children must learn to cope with and not solve the situation.

- One dad actually said there was a hint of relief from the previous uncertainty. The family had been praying for answers for his daughter's sickness. The diagnosis of Lupus, although unfortunate, gave this family some certainty and facts from which to move forward.
- One mother claimed she was devastated when her daughter was diagnosed with blindness. It was at this point she received outside counseling.

- A father admitted his lack of direction by stating, “We didn’t know what to do. Basically, they told us she wasn’t going to be the same person. They gave us a real bad report at first. They scared us.”

Troubling Tubes

The families of the hospitalized children often referred to the difficulty of seeing their loved one with all of the medical equipment. Seeing the loved one in this dehumanizing environment was extremely taxing on their emotional capacity.

The following citations illustrate this fact:

- Referring to her sister’s hospitalization, she reminisced it was “...creepy seeing her with all those needles stuck in her.” When a sibling visited the pediatric intensive care unit (PICU), she said it “...sorta freaked me out seeing her with a tube in her for breathing.”
- According to one dad, “That was the stuff that was hard to deal with,” referring to the at home care for the multiple tubes and drains.
- One sister reminisced, “It was hard for me to see her like she was. She was hooked up to all the machines, and I didn’t know what was going on. I hadn’t ever seen anything like that before.”
- One caretaker could not visit the bedside after the patient was intubated with a breathing tube. This thought instigated negative emotions surrounding previous hospital experiences.
- A sister shared, “I’m not thinking she’s going to be like that. Why’s she got that here? Why’s she got that there? Why is she all hooked up like that?”

- “Don’t tell your friend that you ‘can’t handle’ hospitals, sick people, etc. It’s an excuse. Chances are you can handle it just as well as your friend, and he/she doesn’t want to have to deal with it anymore than you do,” advised one mom.

Disturbing Doubts

The researched families commented on their fears of the ill child’s life being threatened. The families did not openly discuss their fears at the time of the crisis. Several of the respondents referred to these concerns.

- A father recounted, “I didn’t think she was going to make it. We had the priest giving her last rights, and everything.”
- One man remembered all the “tubes hanging out of her.” There was a point at which he was unable to go into the PICU due to his fear that she was going to die. He expressed that he was unable to talk to anyone about his feelings at that time because his perspective would have been awful.
- One sister expressed that concern over her sister’s potential death was the worst part of the whole experience with the illness. Although the family chose not to verbalize the fears, they still remained. “We didn’t want to think like that.”
- A mother expressed her concerns over the uncertainty of the outcome of her son’s surgery. “They didn’t want him to wake up different than when he went to sleep.”
- A mom claimed, “Even if we thought death, we never said it.”

- A mom shared at that time her feelings were, “What’s going on? Is she going to die?”

Impotent Emotions

Family members often reflected on their frustration resulting from an inability to remove the child from the upsetting circumstances. Parents often commented on the regimen they simply wished they didn’t have to enforce.

- One father shared, “It’s hard seeing your child laying there, helpless, and there is nothing you can do. You can’t help them. There is nothing you can do.”
- A mother recalled the helpless feeling resulting from her lack of knowledge, and from the doctors’ uncertainty as to the nature of her son’s tumor. It was extremely difficult not knowing what was best for her son, or the optimal treatment plan. Despite the doctor’s advice to perform surgery, there was an enormous amount of fear of the unknown.
- The heartbreaking realities depict this mother’s lack of control over her life: “I hated giving my daughter shots and I hated holding her down while others tried repeatedly to draw blood from her tiny veins. I hated forcing medications down her that she didn’t like while she screamed and thrashed to try to not take them. I hated digging in her wounds to keep them clean. I hated seeing her intestines when her abdomen was laid open. I hated seeing her medicinally paralyzed and on the ventilator. I hated seeing her go through drug withdrawal in the

hospital. I hated the look in her eyes when she had to watch others eat things that she couldn't (like all solid foods for a while). I hated denying her foods that she wanted because they would be poisonous for her during end-stage renal failure. I hated seeing all of her blood come out of her body, go through the dialysis machine, and back into her body for hours at a time, three days a week. I hated having a hospital set up in my living room (although I hated it less than living in the hospital). I hated missing out on family functions while Maggie was so sick - and I hated resenting anyone who had fun (my sisters both went to London without me!). I hated having to deal with teachers and therapists and nurses and home health aids in my home all the time. I hated forcing enough water down my daughter to perfuse her new kidney every day since the transplant. I hated making her stop eating when she isn't ready to because the prednisone makes her gain too much weight and keeps her hungry all the time. I hated fighting with her dad to get him to give her the same quality of care that I give her and trying to make him understand how important it is. I hated always being 'the bad guy' who makes her do things that are good for her when she doesn't want to do them."

Redefined Realities

The families of children suffering from chronic illness must face new life realities. What once constituted a normal life or routine day suddenly changes dramatically. This theme includes related topics and new realities of the families,

including: multiple medications, sibling issues, financial issues, overwhelmed lives, and new realities at home.

Medication Mania

Extensive medical care is recognized as a hurdle that families with chronically ill children must face (Ray, 2002). The families in this study repeatedly mentioned the excessive amounts of medical care and medications. Ray (2002) noted the parents' difficulty in administering care that was opposed by the child.

- Keeping up with his daughter's medications was an ordeal for one parent. When she is not in the hospital, managing her medications is complicated since she is taking 10 different medications per day.
- One family keeps a medical journal of the child's medications so they can keep track of what medications she has taken. That helps keep things straight when going from one parent's house to another's house.
- One father laughed when asked about his daughter's medications. He retreated to the kitchen and produced a medicine bag full of numerous medications. He explained that all of the information regarding the prescriptions was in the binder that her family takes to each of the young girl's appointments.
- The preteen girl keeps track of her medication schedule.
- The researcher received the following explanation when inquiring if the young girl could get medicine for her nausea. "No, they don't want this one to counteract that one."

Sibling Aside

Siblings of chronically ill children must alter their lives extensively due to the necessities of their ill brother or sister. The well children routinely receive less attention because of the imminence of the needs of the sick child. Frequently, time is sacrificed with the parents since the parents feel compelled to assist the chronically ill child. Some studies indicate that the well child may resent the unbalanced use of time or money between the children (Godshall, 2003). The children in this study recognized differences in their lives due to the illness; however, the siblings but did not verbalize resentment towards the ill child in the interviews. The parents in the study were also cognizant of the balancing act and did their best to meet the needs both children.

- One mother stated her daughter confessed, “I know you love my sister more than me.” The mother tried to alleviate the misgivings.
- A mother tried to make special time with her well child to take her to movies, or conferences, or work together on projects.
- A sibling stated that she was totally happy when she was with her friends. She contrasted her time at home where she is “very to myself” with her school time where she “talks a whole lot.”
- A female sibling would call her mom’s cell phone at the hospital every night to hear her mother’s voice.
- A mother wished that relatives had participated more in the care of her well child’s life. She felt, “Having extended family attend band concerts and things like that might have helped her feel less ‘left out’.”

- A mother noted the sibling was "...very flexible with her schedule - she didn't complain when we would tell her at the last minute to pack up her stuff because she had to go here or there or to spend the night somewhere else than her own home. She also did fairly well in school, making all A's and B's. I was very proud of her. She even was pretty accepting of her sister's illness, care, needs, etc. even when meeting her sister's needs meant that her needs were put on hold."
- A mom referred to going home to see her "other baby". She would try and spend quality time with her daughter, and stay as in touch as possible with the child's needs.
- One sister does not remember feeling jealous or upset due to the time her mother was away with her brother.

Concerned Siblings

The sibling participants expressed concern for the chronically ill children. The siblings shared that their anxieties were heightened during periods of medical crisis.

- One sibling worried about her sister when she was sick; but when she is not sick, it doesn't concern her.
- A sister reflected her concerns by stating, "Most of the time, she was out of it. There was only a couple of times when I went that she was really herself and we had fun like old times, where we laughed and stayed up late at night. You know, being sisters. We had a couple of those times."

- “Really, I would just sit with her. I cried every time I went though,” relayed one sibling.
- When I inquired about a sister’s concern about her sick brother, I discovered that she slept on a palette on the side of his bed for three nights when he returned home from the hospital. Her brother corrected her and said she slept there for three weeks. “He had the nerve to put me out of the room,” she chided. “I kept stepping on her,” he refuted. “I’m concerned about him,” she caringly admitted.

Super Moms

The physical health and well being of parents caring for chronically ill children was notably important according to Beresford (1994). The parents studied in this project, especially the mothers, often remarked that they were expected to function with more power than what they actually possessed. Yet, in observing these same women, it was amazing the resiliency and power that they actually resonated. The following citations are noteworthy:

- “My family expects me to be ‘all there, totally put together’, and I never really feel it.”
- “One part of me thinks ... you just do what you have to do for your child that you love so much. That is true. The other part of me screams, ‘I didn’t ask for any of this and I don’t want it!’”
- Parents of disabled children often feel isolated and lonely (Bradshaw & Lawson, 1978; Melnyk et al., 2001; Quine & Pahl, 1991). One mother

regretted, "...realizing that no matter how bad things got that I really only had myself to rely on."

- A mother felt that she had to handle everything and make all of the decisions. This burden was difficult and made her feel all alone and frustrated with her husband for his lack of support. She confirmed the need for a woman to lean on a man.

Financial Flexibility

The exorbitant medical bills cause families of children with recurrent health issues constant stress. The ability of the family to cope with the economic circumstances is considered a socio-economical coping resource (Beresford, 1994). The families interviewed recognized the added stress, and dealt with it in different manners.

- One mother asserted, "It's a shame to say it, but it seems like you're better off when you don't work. When I was working full time, our food stamps were dropped. When I go to work, I can't make ends meet." She proceeded, "There's something wrong with the system when you can sit on welfare and make it, but if you work, you can't."
- Another mother realized the financial freedom she experienced was only due to an unfortunate lawsuit over her son's death.
- One family declared bankruptcy to deal with their financial overload.
- "You can't worry about everything. You just go on. You have to give it to the Lord," believed one mother. "I still have to buy her medications for her to live. I still have to feed her."

Home Sweet Home

Snowden and Kane (1987) cited the importance of studying families and their day-to-day realities of life dealing with a chronic illness. Worthington (1995) recognized the challenges of families returning home and coping with their new realities. The respondents in this study confirmed the mixed feelings and added responsibilities of returning home with an altered life. The following excerpts exemplify the feelings of the family members:

- In responding to one question, a mother designated the difference between their needs while hospitalized or at home. She answered, “All of the answers below are based on the time we actually spent in the hospital. The issues were different when we were in our "home hospital" and are different now.”
- When returning home after two months away at the hospital, one mother realized, “It was back to reality.”
- A father seemed relieved that his daughter is feeling better at home; currently, the main issue is simply keeping up with her medications. There was extensive at-home care between her hospitalizations. During her period of intensive at-home care, he took a month off work because he “...couldn’t take it anymore.”
- Home life, although better than the hospital offered obstacles of its own. One mother expressed, “I hated having a hospital set up in my living room (although I hated it less than living in the hospital). I hated

having to deal with teachers and therapists and nurses and home health aids in my house all the time.”

- Siblings seemed relieved to be back to a more regular routine when the family members returned from the hospital.

Absence of Authority

In the interviews, it was a common response for the participant to offer a disclaimer of authority or expertise. The family members wanted to help others, and yet admittedly recognized that they were simply getting by. They did not consider themselves experts on this subject. This “getting by” philosophy is mentioned in previous studies (Bregman, 1980; Brown & Hepple, 1989). It was revealing that although the participants did not consider themselves experts on coping, many common themes were consistent among the members. These themes were supported by other research involving families in similar circumstances. Not being an authority on a particular subject does not preclude the possibility of helping others. The ability to openly and candidly express your experiences in a way that others can relate and apply them to their own life is a compelling argument (Lincoln & Guba, 1985). Examples of the participants’ uncertainty were as follows:

- I asked a sibling what advice or help she would offer to other families that have a child with an illness. Her answer, “I wouldn’t really, cause I’m not the expert at all this. I just go along with it. So, I wouldn’t have any say in it.”

- A mother insecurely stated, “We’re dysfunctional. I’m kinda’ mental.” She wondered whether or not the story of her family could possibly enlighten anyone else.
- A caregiver stated that he did not pretend to understand what was best for the ill child. He affirmed that his expertise was in the area of machinery.

Relational Requests

This theme emerged from the families’ recognition and desire for positive relational support and communication from others including medical staff, family, friends, and the call upon God’s help. Subtopics filled with numerous examples serve as an illustration of the relational needs of families experiencing a loved one suffering from a chronic illness.

Call For Communication

The participants in this study expressed their desire for adequate communication. The need ranged from communication with their family members to communication with the medical staff. Ray (2002) stressed the need for clear communication. One parent in the study expressed, “You don’t KNOW what you need. You don’t know what people have to offer” (Ray, 2002, p. 428).

- One mother ensures that her son is informed of procedures the doctors will perform: “Anything they do, I have to talk to him, so he will know.” She finds this honesty about his medical condition is important for her son and has always operated with this in mind when dealing with his illness.

- A sibling was able to talk to her friends at school about her concerns for her brother.
- A mother requested, “Be straightforward if you don’t intend to help in the ways you’ve been asked. Never offer to help and then fail to, especially if they are counting on you to come baby-sit so that they can go somewhere.”

Nice Nurses

The attitude and interactions with the hospital staff affected the families’ outlook on their overall experience. Much research is noted to focus on the health care professional’s role in assisting families coping with hospitalizations (Miles, 1985; Godshall, 2003; Caty, 1984; Balling, 2001; Snowden, 1995). Both the positive and the negative aspects of the interactions with the staff were detailed in the interviews, indicating the importance the families placed on these encounters.

- One child preferred when the nurses and doctors are happy. She wanted them to “...try to help me instead of just poking and poking until they can get it.” She concluded that to help her, they could tell jokes or make her laugh.
- A father appreciated some of the excellent doctors. He cited an example of one doctor staying up all night trying to determine his daughter’s diagnosis.
- A sibling noted that some of the staff interacted well with her sister; the patient had her favorite nurses.

- A mom expressed appreciation by stating, “Some nurses (not all) who (finally) started calling me by my name, rather than ‘mom’, made me feel less like a usable object (or something that is just in the way), and more human.”

Friends and Family

Respondents, without exception, referred to their family and friends throughout the interview process. The appreciation and need of the family support was undeniable. The benefit of family involvement in a child’s hospitalization is recognized in many studies (Caty et al., 1984; Miles & Carter, 1985). The following excerpts reveal the sentiments of the participants:

- One mother does not feel that she could have made it without her family and friends. “Sometimes people just want people there.”
- One mother declared her appreciation for her family’s close proximity and availability to care for her well child.
- Another mom wished that her family could have stayed longer and recognized the amount of pressure she was experiencing.
- The researcher asked one girl what made her feel happy when she was hospitalized. She mentioned, “The things that made me happy was that there was always people by my side. And, people giving me presents saying get well soon.”
- A mother reminded friends and family, “Know that your family loves you and cares about you, but may have a hard time dealing with your excessive praising of your own children making perfect grades,

winning awards, performing some wonderful feat in sports, etc. Be sensitive.”

Please Pray

Each of the families studied referred to their religious beliefs and their hopes that God would heal their child. Research states that religious beliefs play a significant role in the success of families handling stress (McCubbin, 1979). The observed families placed extreme value and appreciation on the fact that others were praying for their families' well being. There were also references made to the role of the church in the lives of the families.

- One mother recommended, “Pray and let the family know you are praying for them.” Yet, she felt that the church she attended had abandoned her family in their time of need.
- A mother instructs her children to “...focus on God and let him lead and guide.” She said we couldn’t question why, but rather focus on God. “He gave me strength even when I was running out of gas.”
- One family “drew upon the Lord” to help them through the stressful times. The father believed, “The Lord has the last say so. You’ve got to stand strong and believe.” That is the summation of his advice to other families experiencing similar circumstances.
- A sibling dealt with the fear of her sister’s death by thanking God and keeping hope that nothing bad was going to happen.

Valuable Individual

This theme reflects the participants' needs and value of their individuality. These personal needs included a need for normalcy in their lives, their feelings of a lack of life, as well as their need for privacy, respect and control in their own lives. The following categories illustrate the participants' views that reflected the importance of their individual needs.

Lack of Life

The families often referred to the daily intricacies of the responsibilities requirements, and competing time commitments that filled their lives. The stringent schedule was consumed with excessive amounts of traveling for most of the families. For the person in the hospital and their caregiver, the walls seemed to close in on them at times.

- One mother wished she could be two places at once.
- One father felt that there was no time for outlets such as working out or stress relief. He said, "I didn't have much of a life."
- A caregiver maintained, "We had no life during this time."

Normalcy Need

Little time is available for the parents of chronically ill children to implement a normal routine in their life. The parents studied recognized this need of normalcy. In the study completed by Bregman (1980), the parents sought to maintain normalcy in the lives of their children suffering from disease. Attempts to maintain some hints of normalcy were referred to throughout the interviews in this study.

- One girl is required to stay out of the sun. She finds this to be inconvenient when she is trying to live a "...regular life."
- One mom recognized her need for exercise. She was unable to implement a workout schedule when her daughter was hospitalized; at home now, she enjoys her personal workout time. It's "...me time. No cell phone, no 'mama this', just me for a couple of hours." She includes the exercise regime in her day about four days a week. She goes in the morning so that it doesn't interfere with her schedule.
- The families attempted to maintain their children's normal lives by continuing their education despite the illnesses, hospitalizations, and disabilities. The siblings also continued their normal at-home routines as permitted.
- Many parents acknowledged their need for a normal setting in which to rest. One mom stated, "Living in a hospital room felt like a prison cell." She would occasionally take walks to break away from the hospital walls.

Independence Declaration

The participants in the study indicated their need to be seen as individuals and have some control and independence over their lives. Although the children appreciate and need the assistance of their parents and medical staff, it was evident from comments they made, that respect for their individuality was desired.

- One child actually drafted a declaration of independence. “I wrote it a long time ago to declare my independence, because I don’t want to be a slave anymore,” she declared. Her family took a trip around Texas and studied history and slavery and Texas’ independence from Mexico. At this time, she realized that she wanted to be independent as well.
- One mother noted, “I hated driving back and forth to the hospital so much, and I hated worse living there and giving up all freedom – and paying those daily parking rates for the privilege!”
- The boy expressed his desire for independence when he revealed his opinions about how his mother had to follow him around because of the stringent rules. “It got boring with mom following me around,” he admitted.
- The parents of the children were appreciative of the children’s need for a social life, and necessary skills to interact socially. This fostered the child’s ability to deal with potential circumstances that the kids may encounter when dealing with other people.
- One child mentioned her need for the nurse’s to treat her as an individual and not just a specimen on whom they were attempting a medical procedure.

Privacy Please

The respondents expressed a need for privacy when in the hospital. The accommodations for the parents were inadequate for their needs. The children

also perceived a lack of privacy. This need is recognized as a perceived stressor identified by children (Boyd & Hunsberger, 1998). The hospital staff was viewed as inconsiderate, on occasion, when exercising the necessary care.

- A parent suggested, “A private hospital room is helpful. Some way of getting some private time to rest. We didn’t have a private room while my daughter was in PICU; that would have been really helpful -- that was a really hard time for me emotionally, mentally, physically.”
- One mother stated there was “...no privacy, no peace, no time to think and reflect - while living in the PICU waiting room with tons of strangers flowing in and out of there all day and night. Worrying about whether my stuff was going to be stolen. Mostly living out of the back of my SUV - leaving my stuff in my car and having to go to it every time I needed something (like a change of clothes).”
- Another mom noted that there was little privacy in the hospital. Even when her daughter was in a private room, the bathroom was shared with the adjoining hospital room.
- A patient remembered that when she was asleep at night, the nurses were taking vital signs and administering medications, which awakened her. “It was uncomfortable for them to keep on doing that. I could never sleep.”
- A parent requested, “Give those involved, live-in parents, some privacy and consideration. The hospital may be where you just go to work, but it is where we live for a while.”

Coping Concoctions

The creative coping strategies and efforts the families employed to manage their new realities are illustrated through the theme of coping concoctions. Some topics that surfaced included: role renegotiation, day-by-day philosophy, perseverance, and the power of positive thinking. Other coping strategies mentioned were the therapeutic usage of art, photography and humor.

Role Renegotiation

Families dealing with a chronically ill child suffer from wide-ranging stress and life changes. The adjustments and added responsibilities often require a renegotiation of roles within the family unit. Marital stress and conflict often occur under such strenuous circumstances (Worthington, 1995). According to Ray (2002) a common realization is, "Some people draw closer, some drift away, but all relationships change" (p.431). The researched families commented on the adjustments in their family structure.

- One participant felt the illness created confusion as to the various roles each partner played.
- A parent concluded, "I think people don't realize that the family left at home is missing an adult caregiver who helps with the cooking, cleaning, paying bills, mowing the lawn, etc., and that the people left behind have to make up for all these tasks, perform their own roles, plus visit the family in the hospital and support them as well. Anything they can help with, either directly for the family at the hospital, or

indirectly with the family supporting the family at the hospital, would help enormously.

- A mother who owned her own business renegotiated her work schedule to meet the demands of the hospital stay. All of the caretakers made adjustments in their roles to assist with the newfound needs.

Day By Day

Other studies have suggested that families coping with a child with a chronic illness execute a day-by-day mentality (Bregman, 1980; Brown & Hepple, 1989). They simply take the challenges as they come. There is often not a significant focus on the long-term issues. This philosophy was evidenced in comments that the respondents offered.

- One mother noticed that times just seemed better when she would “...go with the flow.” Clawson (1996) concluded that families who recognized the necessity and possessed the willingness to change were able to successfully adapt.
- A mother advised other families to try and focus on the day at-hand and not worry about the future.
- A mother recognized the futility of worrying about tomorrow. She realizes, “You plan today. It could be totally different than what you think.”

Just Do It

In keeping with previous research, several participants commented on the necessity to persevere, despite the obstacles. There was a realization that, at times, they didn't know how they persisted; they just endured. The need to keep going was presented by parents in related studies (Ray, 2002).

- A father remarked that his family hated to see his daughter sick, but that they have had to get used to it.
- A sister concluded about her visits to the hospital room that she “had to deal with it.”
- A father recommended, “Before you get to panicking and all of that, learn what it is, and see what you’ve got to do. It’s going to hurt. It’s going to make you feel sad. But...”
- One mom believed that they have just done what they have to do in order to survive their circumstances. She believed there here hasn’t been anything heroic about the techniques they have used to cope with the circumstances.
- “I just took it on as this is something that has to be done, and I did it. I didn’t attach any emotional baggage to it. I just did it,” referred one caregiver.
- Coping is management of a problem, and not mastery of a problem (Lazarus & Folkman, 1984). One child demonstrated her realization of these facts in her quote, “It really don’t hurt no more now that I’m used to it.”

Positive Power

The assessment of a situation or the individual's appraisal of a situation determines whether or not that circumstance is perceived as stressful, according to the process model of coping presented by Lazarus and Folkman (1984). Focusing on the positive aspects of the child's illness and the family's situation is associated with positive adjustment (Beresford, 1994). The researcher observed this phenomenon on a number of occasions throughout the interview process with the different families.

- One example was when the child, who suffers from Joubert Syndrome and the numerous ailments she has experienced secondary to the syndrome, was asked what was hard in her life. She assuredly answered that it was hard to keep her sister neat and that getting ready for choir is "a pain in the butt." She expounded that you had to keep up with the group. In the scope of her life, these events were the ones that immediately surfaced in her mind as being difficult. We laughed together at her response to this question.
- One mother quoted her daughter's advice to her, "Face the bright side mom." When her mother asked, "What's that?" she replied, "The other side of the mysterious darkness."
- The adolescent boy also illustrated the power of positive thinking when he offered the reason for the transition from recovery from his first brain surgery to the following surgeries. He realized that the sooner he got up and walked around after the procedure, the sooner he would get

to go home. This also exemplifies the importance of being home for this boy.

- Other examples of positive thinking occurred in the mention of faith in the families. On more than one occasion, the various participants commented that they had to focus on the positive, and pray for complete recovery. The mother's request for prayers when closing her e-mails to friends and family further illustrates this fact.
- One mother commented on a number of occasions about raising her daughters to look at the positive side of situations.
- One chronically ill participant proved her positive attitude in her outlook by noting, "The good thing is I am starting a new life. I ended my old one a few months ago, and I'm starting a new one." Her old life consisted of kidney failure, hemodialysis, peritoneal dialysis". Her new life is "a whole lot better". It includes acting, being active, playing, watching the news, reading the newspaper and magazines and books.
- This positive outlook was literally the basis for one family's religious beliefs. Even if someone thought death, one mother did not want to hear it at that point. She also did not like it when someone came and prayed for God's will. She believed in claiming that her daughter would get well.

"Photo-Therapy"

A consistent theme among the families was the collection of memories through photographs. In each family, without the researcher's inquiry, the

members specifically requested to show photographs depicting their lives. The photos portrayed a more comprehensive view of the lives of the participants. On every occasion, the members crowded around enthusiastically when the photographs surfaced. The members laughed, discussed, and debated over the events pictured. The family and the happenings in the photos became almost life-like, as their descriptions were perfectly apt. The photos exemplified both good times and sad ones. The collections of the families' photos included, but were not limited to the following topics: birthday parties at the skating rink, birthday parties in the hospital playroom, shaving hair after chemotherapy, a family get-together at the grave of the deceased child, silly amusement park photos, photos from the sibling group at the Joubert Conference, a portrait of the preteen wearing the braid-wig her mom had made, a and an orchestra performance.

- One mother shared, "I am big into picture-taking to the annoyance of my older daughter; I have photos of every aspect of their lives, good and bad."
- One family rushed to get photos and look for specific pictures to illustrate their descriptions to the researcher.
- Several of the children eagerly took pictures off the wall to share with the researcher.

Heart Art

The study participants mentioned using art to express their emotions. It was apparent art was a medium that a number of participants utilized in their

coping process. This technique is noted to be a positive coping strategy for hospitalized children (Boyd & Hunsberger, 1998).

- A boy frequently drew in the school at the hospital.
- A female patient also mentioned that she used art to express her emotions. She quoted, “I like drawing. It helps me express the way I feel. I’ve been practicing for a while.”
- One child spoke a great deal about art helping her express herself.
- A sibling also used art as a tool of expression. She said that she scribbles when she is upset. Although she said she had never actually drawn what happened with her sister, that memory remains in her head. There was one special picture of her life that she would only share with her best friend.
- An artistic portrait, that her uncle drew of her, covers the binder that held all of one patient’s hospital information and facts about her illness.

Humor Helps

Stress is often countered with a sense of humor. It is considered a coping resource for parents of a disabled child (Farran et al., 1986; Libow, 1989). This coping strategy is shown to be helpful when dealing with stressful situations (Brown & Hepple, 1989). The research participants appreciated humor. This was evident through interactions with one another and with the researcher; observations and opinions also placed value on humor.

- She mentioned that she likes it when the nurses and doctors are happy. She wanted them to “...try to help me instead of just

poking and poking until they can get it.” To help her, they could tell jokes or make her laugh.

- One father clearly and distinctly remembered and reenacted the doctor’s presentation at the time of diagnosis. He used humor to restructure an event that was traumatic at the time. “It was like watching the stories. When the doctor would get to the good part, he would pause and break for a commercial.”
- One young lady repeatedly added wisecracks to the dialogue such as: “I feel like a total out-of-control maniac.”

Awareness & Advocacy

Once the families were encountered with the new reality of a chronic illness, the members sought information for their own use, as well as to advocate for the child’s special needs. The parents utilized their newfound education to advocate for involvement in the child’s medical care, opportune educational experiences and many other areas in the ill child’s life.

Need for Knowledge

Parents and families of chronically ill or hospitalized children are bombarded with unfamiliar diagnoses, facts, and medical procedures. The parents often cannot afford the luxury of time in important decision-making situations. Studies have repeatedly recognized the importance for the families’ need of information (Snowdon, 1995). Families in this study frequently referred to the need for or lack of information.

- One mother instructed, “Do not hide or refuse to share information with parents. It is not the doctor or nurse’s job to ‘protect’ parents from the extent of their child’s illness and prognosis. Health care professionals do not know parents well enough to be able to determine whether their needs are best served by disclosing or refusing to disclose information. Give them what they ask for.”
- A mom suggested one avenue a friend could assist the family. “Perform internet searches for information that might help the family. Don’t send the website link - send a photocopy of the articles.”
- A family member admitted, “...learning more medical stuff than I ever cared to.”
- One prominent observation was a “lack of needed information.”
- A sibling recounted the family’s confusion at the time of diagnosis. She remembered that none of them had ever heard of anything like it, nor did they know what to do about it. She shared that she had no clue what was going on and that her mother did not talk about the details very much.

Family Friendly

The families stressed the importance of their involvement in their child’s care. This issue surfaced on a number occasions throughout the interviews. It was also evident through observation of the amount of time the families spent at the hospital, as well as their efforts to coordinate their lives to meet these demands. The results of this study are consistent with the previous research

concerning family involvement in the care of hospitalized children (Caty et al., 1984; Hostler, 1991; Miles & Carter, 1985). The following examples capture the participant's thoughts:

- “Don’t make treatment decisions based on your prejudices about whether a parent can implement them or not – ask first. I am a smart person and should be given options. Doctors should discuss with me what would work best for my family, and not make unilateral decisions.” Parents of hospitalized children desire the respect of the healthcare professionals regarding their expertise about their child (Balling, 2001).
- One father’s biggest complaint about the hospitalization was that the parents were not allowed in the room at all times with their child. Realizing the confidentiality reasons for this rule, he retorted, “What they don’t understand is parents don’t care about what’s going on with the child beside them. They want to know what’s going on with their child.”
- One family felt that the child fell out of her bed in the PICU due to the prevention of family’s presence.

Education Issues

Educational opportunities were expounded upon throughout the various interviews. The families involved offered insight into the educational opportunities and obstacles.

- One mother referred to keeping her daughter's education going while in the hospital by noting, "It was hard to work with her in her weakened condition without any of her equipment (CCTV, etc.)."
- "Work with, not against, the family in providing quality services to the child in whatever setting - hospital, home, school," suggested one mom after frustrations in dealing with her child's education.
- A mother appreciated the hospital system enrolling her son in the school services at the hospital. This patient, along with the other ill children, received school lessons during their extended hospital stays.
- In referring to the teacher's lack of empathy for his daughter's illness, one father questioned, "If she's sick, and that's gonna' kill her. What are you trying to do, kill her? Use your head! If that was your child and she was sick, would you do that to her?"

Parent Power

The parents in the study unexpectedly encountered circumstances that required them to almost function with superhuman powers. What were once taken-for-granted abilities of their children were now seen as enormous challenges or even impossibilities. Whether facing education issues, health issues, or social issues, these parents go to great extents to promote the best interests of their children (Ray, 2002). Research reported that an estimated 50% of parents' care giving time was spent advocating for their child's special needs (Ray, 2002). Parents of chronically ill children are faced with responsibilities that often require new skills and complex care, as indicated by statements below:

- “Being totally responsible for managing the medical nightmare - it was a little too much. I shouldn’t have to pay the light bill on the same day that I have to make some life altering decision about my daughter’s medical care.”
- A parent advised, “Listen to the parents. They know and care about what is in the best interests of the child. Don’t treat them like what they say is of no importance.”
- One father acknowledged, “If you break down, how can you be strong for your child? You can’t give up and lose faith.” He did not want his child witnessing his discouragement.
- The education of others about the child’s illness is seen as an integral element in the family’s adaptation process (Canam, 1993). All of the involved parents informed nurses and school authorities of their child’s condition and needs.

RECOMMENDATIONS

Further research is recommended into the personal experiences of families with chronic illnesses. This research supports the notion that “general” findings can be learned from families with different types of chronic illnesses. Meleski (2002) commented on the importance of the “generic approach.” Although there is benefit in specific interventions for families with a specific illness, this research project illustrates the similar challenges and hurdles that families with different illnesses encounter. These commonalities provide a basis for a larger support network of people to assist one another in addressing the

needs of the families. Although the children in the study each suffered from various illnesses, the responses, concerns, complaints, and ideas seemed to be consistent. Research following the generic approach would further the insights into how to assist families in coping with chronic illness.

It is also recommended that researchers consider the aspects beyond the hospital stay when studying families with a child with chronic illness. Much research exists concerning hospitalization (Snowdon, 1995; Caty, 1984). The families in this study touched on both the at-home life and the hospital life. Additional studies focusing on how families that cope effectively deal with the at-home challenges could be of additional assistance to families.

It is further recommended that researchers go beyond the “educational and research” setting to provide easy-to-read help for parents undergoing such challenges. The families are bombarded with learning medical terminology and facts that were previously irrelevant information in their lives. The necessity of learning this new and highly pertinent information does not meet the emotional needs of the parents and family. The researcher believes that informative, easily understood “what to expect” and “how to survive” books would be appreciated by parents and families undergoing the life challenges of facing a child coping with a chronic illness.

CONCLUSION

It seems somewhat of an injustice to attempt to summarize and conclude such an in-depth and emotionally charged study. Erlandson, et al (1993) recommend that the researcher’s principal responsibility is “...to communicate a

setting with its complex interrelationships and multiple realities to the intended audience in a way that enables and requires that audiences interact cognitively and emotionally with the setting” (p. 163). Through participant observations, interviews, and review of documents, the lives of families undergoing a child experiencing a chronic illness have been examined. The insight that these families shared allows the reader to transfer the knowledge to their own experiences and trials in life.

This research project depicted the experiences of families dealing with their child’s chronic illness. Each of the children studied experienced life-threatening illnesses. The case study method allowed the researcher an opportunity to interact with the participants and vicariously share their circumstances. Through their willingness to convey their innermost thoughts and fears, the respondents have offered an authentic experience to the reader. A good respondent is sensitive to the culture of their circumstances, and is able to relate it in terms others can understand (Erlandson et al., 1993).

Related documents and articles offered an even more extensive view of the multiple realities that the researched families encountered. The following pieces of information were among those examined: internet informative handouts regarding illnesses, photographs, teacher’s letters, hospital bills, letters to siblings, and pictures drawn by family members.

The diversity of the life circumstances of these families was highlighted in the numerous emergent themes. The families, although experiencing unique illnesses, depict the commonalities of their needs, feelings, frustrations, and fears

throughout the coping process. These multiple realities surfaced from the implementation of the generic approach. The findings of this type of study have the potential to help families by concentrating on coping strategies, supplying health care team members with valuable goals for parents, and providing a basis for future improvement (Meleski, 2002, p.49).

This research project was undertaken in hopes that the reader could interact with the realities of the lives of the participants in such a way that it would compel him or her to action. Whether the action is to consider their attitudes about life, begin to offer assistance to others in need, research further on the important topic, or simply recognize the realities that families under such circumstances survive; it is desired that action will follow.

The researcher was touched by the case studies of the individuals examined. The participants, although admittedly insecure about their abilities, related their stories in an effective, insightful manner. The individual styles varied as much as the personalities of the participants. The diversity of the respondents rendered even more insight into the commonalities of families experiencing similar situations. The emergent themes illustrate the common needs and coping strategies in families with children experiencing a chronic illness. It is the researcher's belief that the study of the multiple realities of these lives cannot be "concluded," but rather, "captured."

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APPENDIX

A Description of Experiences of Families Coping with Chronic Illness in a Child.

Interview Protocol

Interview Protocol for Child Participant

1. If I were you, what would my usual day be like? What would I do? What would I think? What would I feel?
2. Can you tell me about your illness?
3. Describe some of the good things about your life. What are some of the hard things about your life?
4. How does your family deal with difficult things? During a difficult time, what things help your family? What things make life harder for your family?
5. What would you tell the following people if they were trying to help someone in your situation: family members, doctors and nurses, teachers, friends or other people you can think of that you know?

A Description of Experiences of Families Coping with Chronic Illness in a Child.

Interview Protocol

Interview Protocol for Adult Participant

1. Tell me about a typical day in your home dealing with a child with a chronic illness.
2. Describe some of the adjustments or obstacles resulting from your child/relative's illness.
3. As a parent/relative of a child with a chronic illness, what do you feel helps the family cope with the circumstances? What things make it difficult?
4. What recommendations or suggestions do you have for the following people when helping a family that has a child with a chronic illness: health care professionals, educators, family members, formal support groups, friends, or other individuals they may interact with?

A Description of Experiences of Families Coping with Chronic Illness in a Child.

Interview Protocol

Interview Protocol for Sibling Participant

1. Tell me what you do each day in your home with your brothers/sisters.
2. Are there things your family does because your brother/sister doesn't feel well sometimes?
3. How does your family deal with difficult things? During a difficult time, what things help your family? What things make life harder for your family?
4. What would you tell the following people if they were trying to help someone who had an illness in their family: family members, doctors and nurses, teachers, friends or other people you can think of that you know?

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